

Guyana



**Factors that Influence Women's
Uptake of PMTCT Interventions in
Georgetown, Guyana**

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**Ministry of Health
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Additional information about the MEASURE *DHS+* project can be obtained from MEASURE *DHS+*, ORC Macro, 11785 Beltsville Drive, Calverton, MD 20705 (telephone: 301-572-0200; fax: 301-572-0999; email: reports@macroint.com; internet: www.measuredhs.com).

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EXECUTIVE SUMMARY

HIV can be transmitted from the mother to the baby during pregnancy, labor, delivery, and the postpartum period. Prevention of mother-to-child transmission of HIV (PMTCT) programs—HIV counseling and testing, antiretroviral (ARV) prophylaxis at delivery, and counseling and support on family planning and breastfeeding practices—have been developed to prevent this transmission.

In Guyana, it is recommended that pregnant women first come to the antenatal care (ANC) clinic in the first 12 weeks of gestation, followed by monthly visits up to 28 weeks, bi-weekly visits from 28 to 32 weeks, and weekly visits from 32 weeks until delivery. PMTCT services are provided through ANC and postnatal care clinics at health centers and also through the Georgetown Public Hospital Corporation labor and delivery ward. Most women are offered voluntary HIV counseling and testing at their first ANC visit, and a follow-up test is offered at 32–34 weeks gestation or after 3 months (window period) if their first test is negative. Counselors also encourage testing of the woman’s partner. Because the HIV test is laboratory-based, it requires at least two ANC visits by the woman: one to take the test and another to receive her results and post-test counseling. ARV prophylaxis—a single dose of nevirapine given to the woman during the first stage of labor and to her baby within 72 hours after birth—is available only at the hospital labor and delivery unit.

The goal of this study was to learn why women attending ANC clinics that offer PMTCT services do or do not complete HIV counseling and testing and, if they test positive, why they do or do not receive ARV prophylaxis. By identifying these reasons, program planners and providers can learn how to gear program policies and clinic practices to enable more women to take steps to prevent transmission of HIV to their babies.

Methods

This qualitative study, conducted in two phases between April and the end of September 2005, involved collection of data from reviews of clinic and hospital records, observations of clinic practice, and in-depth interviews with 89 women (34 HIV positive; 55 HIV negative) who attended an ANC clinic at a study health center in Georgetown. Women were interviewed on a broad range of topics related to their experience with HIV testing and counseling and, if HIV-infected, receipt of nevirapine.

HIV Testing

Most women began attending ANC during their first or second trimester and attended most scheduled appointments. There was widespread knowledge among the women that they would be offered an HIV screening test at ANC. The majority of women received the result of their first test at the clinic before delivery, although some women who said they were tested twice reported that they did not receive the result of their second HIV test before delivery; a few women never received any test result.

Nearly all women attending ANC accepted HIV testing, if not initially then at a later point in their pregnancy, and most women said that their acceptance of HIV testing was voluntary. Only two women refused the test, saying they were afraid they were infected with HIV and did not want to know their HIV status.

Knowledge that vertical transmission of HIV occurs was high, and the desire to prevent infection of the baby was the main reason women gave for accepting the HIV test. Despite this general knowledge, most women could not say exactly how or when transmission of HIV to the baby would occur, and most women did not understand the concept of the window period. Both of these findings suggest a need for strengthening counseling messages provided to the women during counseling.

A few women who tested HIV positive did not disclose their HIV status to anyone for fear of physical violence from their partner, being put out of the house, or losing a job. Those women who thought they might be assaulted by their partner also thought that they might have infected him.

Although testing of the women's partners was encouraged by ANC clinic staff, most male partners did not come to the clinic to get tested. Some women said their partner took the woman's test results, whether positive or negative, as a reflection of his own HIV status and did not feel the need to get tested, suggesting the need to emphasize the concept of discordant couples during counseling sessions.

ARV Prophylaxis

Most women who tested HIV positive reported that ANC staff encouraged them to go to the hospital at the first sign of labor so they could receive nevirapine in time. However, some women arrived at the hospital too late to receive nevirapine, citing problems obtaining transportation, anticipation of a long wait on the wooden benches in the check-in area before being admitted to the labor room, and waiting for a complete set of labor signs as reasons why they delayed leaving for the hospital when labor began.

Service-related reasons for why women did not receive nevirapine included that the woman did not bring her ANC card to the hospital and that the HIV test result was not recorded on the woman's ANC clinic card or was misunderstood. In fact, three HIV-infected women did not have even one HIV test result indicated on their ANC cards at the time of delivery, even though they had been tested. In one case, a woman did not receive nevirapine because the hospital staff was too busy to administer the drug in time.

One HIV-infected woman stopped attending ANC after hearing her positive results but before post-test counseling; she was therefore unaware that she and her baby needed nevirapine to prevent HIV transmission.

Conclusions

Most women attending the health centers in Georgetown began attending ANC early enough to receive HIV testing and counseling, and most women were willing to take the HIV test and receive their results. The failure of women to reach the hospital in time and of providers and

women to consistently use the ANC clinic card system were the biggest reasons why women who tested HIV positive did not receive nevirapine at delivery.

Recommendations

The following recommendations are based on the findings of this study.

- Update the national PMTCT protocols to ensure that all women who come for ANC, regardless of the length of their pregnancy, are tested for HIV and receive their results:
 - Use rapid testing where possible to increase access to HIV testing. In places adopting rapid testing, a quality control algorithm could be added to reanalyze a percentage of negative tests with enzyme-linked immunosorbent assay (ELISA) tests.
- Add PMTCT program components to ANC and delivery care services:
 - Increase information, education, and communication (IEC) and counseling efforts to encourage pregnant women to receive ANC starting with the first trimester. Promote the idea that HIV testing is a standard part of ANC and is important to ensure an optimal pregnancy outcome for the mother and child. Women who deliver at home should be counseled to receive HIV testing when they first bring their infant in for vaccinations or other care. Health care providers should use ANC visits, as well as deliveries, as opportunities to educate women about HIV transmission and prevention.
 - During counseling sessions, emphasize the concept of discordant couples.
 - Provide added privacy in the labor and delivery units for the administration of nevirapine.
- Improve PMTCT record keeping for ANC and delivery:
 - Strengthen communication between HIV testing services and the ANC and delivery units. Use color coding or some other unobtrusive system to ensure that positive laboratory results are linked to patients' hospital records and ANC cards.
 - Keep up-to-date registers of HIV-positive results among pregnant women in the ANC and delivery units, for quick checking during ANC consultations, labor, and delivery.
 - Include registry of the administration of nevirapine on delivery records (e.g., partograms, hospital records) and ensure linkage with PMTCT records.

- Enhance training for health care providers on HIV testing:
 - Provide in-service and pre-service training for health care providers emphasizing the importance of checking whether pregnant and postpartum clients have been tested for HIV, and offering HIV testing to all clients who have not been tested.
 - Provide special training to PMTCT providers on counseling skills, protecting clients' privacy and confidentiality, and maintaining a positive attitude with clients. These skills should be included in on-the-job guidelines for optimal provider performance.
- Reduce HIV-related stigma:
 - Behavior change campaigns should emphasize not only that HIV cannot be transmitted through casual contact—such as sharing food with people who are HIV positive—but that because of recent advances in the treatment of AIDS, people who are HIV positive can now live a long time and have a good quality of life. Such messages will encourage women to take advantage of PMTCT services.
- Community outreach:
 - Consider setting up a system involving community outreach or health workers to follow up on pregnant women who test positive but do not keep their scheduled ANC visits, or do not deliver at the expected health institution.
 - Help HIV-infected women develop a transportation plan to assist them in keeping their follow-up ANC visits and in bringing their infants to receive nevirapine within 72 hours postpartum.

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ARV	Antiretroviral
CDC	U.S. Centers for Disease Control and Prevention
FHI	Family Health International
GHARP	Guyana HIV and AIDS Reduction Project
GPH	Georgetown Public Hospital
HIV	Human Immunodeficiency Virus
MOH	Ministry of Health
PAHO	Pan-American Health Organization
PMTCT	Prevention of Mother-to-Child Transmission of HIV
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on AIDS
UNICEF	United Nations Children’s Fund
USAID	United States Agency for International Development
VDRL	Venereal Disease Research Laboratory test or laboratory test for Syphilis
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

This study, funded by the U.S. Agency for International Development (USAID)/Guyana, examined women's experiences using services for prevention of mother-to-child transmission of HIV (PMTCT) offered through public sector antenatal care (ANC) clinics and the central referral hospital in Georgetown, the capital of Guyana. The goal of the study was to learn why women who attend ANC clinics that offer PMTCT services do or do not complete all of the recommended PMTCT interventions, namely HIV counseling and testing during pregnancy and antiretroviral prophylaxis (ARV) at the time of delivery.

1.1 Background

The population of Guyana is mainly East Indian (43%) and African (30%), with smaller numbers of mixed ethnicity (17%), Amerindians (9%), Portuguese and Chinese. About 94% of the largely rural population live in the six coastal regions. More than half of the population (57%) are Christians; the remainder are Hindu (28%), Muslim (7%), or other (8%). The official language is English, but Hindi, Urdu, and Amerindian languages are also spoken (Guyana Bureau of Statistics 2002).

Georgetown is the capital and major urban center of Guyana. Georgetown has more than a dozen different neighborhoods, each with its own public health center that provides a wide range of health services, mostly free of charge, to the residents of the neighborhood. At the time of the study, the public health centers were administered either by the Guyana Ministry of Health (MOH) or by the Municipality of Georgetown and were open during the day on Monday through Friday. Qualified medical personnel are in short supply in Guyana because staff emigrate to better paying positions in the Caribbean, Great Britain, and the US. Because of the shortage, nurses, nursing assistants, HIV counselors, medex (similar to a physician assistant), and physicians rotate between two or more clinic locations each week. ANC clinics are held at the health centers on one or two mornings each week.

Georgetown Public Hospital Corporation, located in central Georgetown, is the country's central referral hospital and is also where women attending government clinics in the area are directed to deliver their babies. This hospital is heavily used, with an estimated 19,000 inpatients per year (Donald Ardiel Architect Keeler and Associates).

The Caribbean region is currently one of the areas most profoundly affected by HIV/AIDS, second only to sub-Saharan Africa in its HIV prevalence rates. Current epidemiological statistics for the Caribbean estimate that 300,000 people are living with HIV/AIDS, including 30,000 who became infected in 2005 (UNAIDS, 2005a). The primary routes of HIV transmission in the Caribbean are believed to be heterosexual and male homosexual penetrative intercourse (UNAIDS, 2005a). The exact prevalence of HIV infection in Guyana is unknown; however, the MOH estimated the HIV prevalence rate at the end of 2004 to be about 2.5% (Government of Guyana National HIV/AIDS Programme, 2004). The World Health Organization (WHO) estimates that the prevalence of HIV infection in the adult population ranges between 0.8 and 7.7% (WHO, 2005). Data from the antenatal seroprevalence survey showed that approximately

2.4% of pregnant women are infected with HIV (Government of Guyana National HIV/AIDS Programme, 2004).

HIV can be transmitted from the mother to her baby during pregnancy, labor, delivery, and breastfeeding. Programs for prevention of mother-to-child transmission of HIV (PMTCT) are rapidly developing worldwide. Basic PMTCT programs vary by country, region, and even district, and are often organized according to how ANC and other health services are being provided. However, the basic programs usually consist of HIV counseling and testing (with education in safe sex practices), ARV prophylaxis, and counseling and support on family planning and breastfeeding alternatives. Successful use of all these interventions substantially decreases the chances that a woman who tests positive for HIV will pass the virus to her baby (UNAIDS, 2005b). In addition to these three interventions, programs called “PMTCT Plus” also encourage the woman’s partner to accept HIV counseling and testing. If the woman or her partner are found to be HIV positive, ARV is offered at that site or they are referred to an appropriate care and treatment site. Other health care services, such as family planning, may also be offered.

1.2 PMTCT Services in Guyana

Guyana’s PMTCT services include all three key interventions, and at the time of the study there were plans to scale up to PMTCT Plus programs in the near future. All PMTCT services supported by donors (e.g., President’s Emergency Plan for AIDS Relief [PEPFAR] through USAID/Guyana HIV and AIDS Reduction and Prevention Project [GHARP] and U.S. Centers for Disease Control and Prevention [CDC], Pan-American Health Organization [PAHO], United Nations Children’s Fund [UNICEF]) are provided through ANC and postnatal care clinics held at health centers and through the Georgetown Public Hospital Corporation labor and delivery ward.¹ In 2001, the MOH piloted the PMTCT program at 11 sites in four regions of Guyana. At the time this study was conducted, 27 health centers located in four regions offered PMTCT services through their ANC clinics.

In Guyana, it is recommended that pregnant women first come to the antenatal care (ANC) clinic in the first 12 weeks of gestation, followed by monthly visits up to 28 weeks, bi-weekly visits from 28 to 32 weeks, and weekly visits from 32 weeks until delivery. PMTCT services are provided through ANC and postnatal care clinics at health centers and also through the Georgetown Public Hospital Corporation labor and delivery ward. Women are offered voluntary HIV counseling and testing at their first ANC visit, and a follow-up test is offered at 32–34 weeks gestation or after 3 months (window period) if their first test is negative. Counselors also encourage testing of the woman’s partner. Because the HIV test is laboratory-based, it requires at least two ANC visits by the woman: one to take the test and another to receive her results and post-test counseling. ARV prophylaxis—a single dose of nevirapine given to the woman during the first stage of labor and to her baby within 72 hours after birth—is available only at the hospital labor and delivery unit.

¹ Most pregnant women (over 80%) in Guyana attend ANC, and an even higher percentage (over 85%) are attended by a skilled provider in a hospital at delivery (Guyana Bureau of Statistics and UNICEF, 2001).

Counselors encourage testing of the woman's partner, and HIV-infected women receive counseling on ARV prophylaxis and infant feeding, as well as information on the signs of labor and the need to reach the hospital in time to receive ARV prophylaxis. Currently, ARV prophylaxis is available only through labor and delivery units in hospitals. Nevirapine² is given to the mother during the first stage of labor and to the baby within 72 hours of birth. Postnatal clinics conduct follow-up testing of the infant and offer guidance on breastfeeding, including provision of breast-milk substitutes if the woman chooses not to breastfeed.

1.3 Purpose and Objectives of Study

Preliminary statistics from the 17 PMTCT sites in Guyana suggest that most pregnant women (86%) agree to HIV testing when offered it at their initial ANC visit, and the majority receive their results. Although the program has made substantial headway in gaining women's participation in PMTCT prevention activities, only 60% of women testing HIV positive receive nevirapine during labor, and only 83% of their infants receive nevirapine within 72 hours after birth (personal communication, PMTCT Coordinator, Guyana MOH, 2005).

This study was exploratory in that it sought to identify possible reasons why women may not receive HIV testing and counseling, and if HIV infected, why they (and their baby) may not receive ARV prophylaxis. Because so many factors may be involved in why women are unable to complete all of the recommended PMTCT interventions, women were interviewed on a broad range of topics. Besides discussing topics related to their general use of ANC and delivery services, women were asked about their experiences with HIV testing and counseling, disclosure of their test results, labor and delivery experiences, hospital experiences, and receipt of nevirapine at the time of delivery for their most recent pregnancy.

By identifying the reasons why women did or did not complete all recommended PMTCT steps during their most recent pregnancy, program planners and providers can learn how to gear program policies and clinic practices to identify HIV-positive women and enable them to take all possible steps to prevent transmission of HIV to their babies.

² The nevirapine regimen used in Guyana is currently favored in developing countries because it is simple to administer and costs less than other regimens. In addition, the rapid uptake and long half life of the drug (61 hours in the woman) make it more effective than some other single-drug options (Guay et al., 1999).

CHAPTER 2

METHODS

An MOH steering committee—including the Director of Maternal Child Health, the PMTCT coordinator, the Chief Nursing Officer, and the Director of Infectious Diseases—was convened to guide the study. The committee, which met several times between February and April 2005, participated in developing the study objectives and selecting the study sites, assisted with solving problems during fieldwork, supplied service statistics, reviewed drafts of the report, and made recommendations.

During the planning stages, nine members of the Macro Institutional Review Board reviewed the study proposal for any possible infringement of privacy rights. Elaborate precautions, including limiting access to participant lists and use of multiple consent forms, were used to protect the participants from any inadvertent disclosure of their HIV status. The interviewer did not know the woman's HIV status prior to meeting with her for the interview.

2.1 Overview

The study was conducted in the Georgetown area.³ Health centers with ANC clinics were selected according to the volume of ANC clients and the number of women who had been identified as HIV-infected.⁴ The Georgetown Public Hospital Corporation labor and delivery ward was also a study site, because all women from PMTCT ANC sites in Georgetown are directed there for delivery. This is also where HIV-infected women must go to receive nevirapine.

The study was conducted in two phases: Phase I focused on collecting data related to HIV testing experiences, and Phase II focused on HIV testing experiences as well as delivery experiences and receipt of nevirapine by women (and their babies) who tested HIV positive during ANC. Data were collected using individual interviews, clinic and hospital record review, and clinic observation. In Phase I, the clinics' patient registers and PMTCT log books were reviewed. The patient register and PMTCT log book list all the patients attending the ANC clinic, but the PMTCT log book does not contain addresses or identifiers other than a woman's name. Women are logged into the PMTCT book when they begin attending the ANC clinic for their current pregnancy, and the results of their screening tests, including both HIV tests, is recorded. In Phase II, the hospital labor and delivery ward's PMTCT log book was reviewed. This log book lists all HIV-infected women presenting to the labor and delivery ward and includes the name of the woman, the date of delivery, and whether the woman and baby received nevirapine.

³ The steering committee recognized that variability would likely exist in other regions of the country and recommended that a regional comparison study be conducted. Given the budget limitations of the project, Georgetown was developed as the focus, and the MOH assisted in selecting the best Georgetown sites.

⁴ The steering committee eliminated Georgetown ANC clinic from the study because it was more interested in understanding the dynamics in neighborhood community-based sites than in the central referral center that received patients from all over the country.

Topic guides with closed- and open-ended questions were used to guide the interview process in both phases of the study. Answers to some questions, such as, “When did you begin antenatal care for your current pregnancy?” were considered essential and these answers were briefly probed. Other topics were explored in greater or lesser depth as the flow of conversation allowed. With permission from the women, the interviews were tape recorded and later transcribed verbatim. Each woman’s transcript was assigned a number, and the results were analyzed using a Microsoft Excel spreadsheet and ATLAS.ti, a qualitative analysis program.

2.2 Phase I

2.2.1 Phase I Recruitment

Initially, the methodology for Phase I called for recruiting women who declined HIV testing, as well as women (matched by age, parity, clinic, and date of first ANC visit within one month) who accepted an HIV test. The two groups were to be selected from the ANC clinics’ PMTCT log books at five Georgetown ANC clinics offering PMTCT services. However, a preliminary review of the log books, before any fieldwork began, revealed a very high rate of acceptance of the test and a noteworthy number of women who initially refused but later accepted testing. Very few women refused HIV testing altogether during pregnancy.

A decision was made to modify the methodology to determine why women accept the test so readily and why women who initially refused the test later accepted it. Therefore, women in their third trimester or who had delivered within the last six months were recruited for the study directly from the ANC and postnatal care clinic waiting room at three health centers, referred to as site 1, site 2, and site 3 for anonymity. These women were chosen because they had been through the entire PMTCT process and could relate their experiences. Only three health centers were needed to recruit enough participants to reach the sample goal of 45 women (15 from each site).

Interviewers visited each clinic during ANC and postnatal care clinic days and worked closely with the nurse recruiter hired at each clinic to solicit interviews from women for the study. As each woman checked in at the front desk for her appointment, the nurse recruiter screened her to determine her eligibility for the study (i.e., in third trimester of pregnancy or within 6 months postpartum).

If the woman was eligible for inclusion, the nurse recruiter briefly described the study and asked whether the woman would be interested in participating in an interview following her clinic appointment. If she agreed, the interviewer escorted the woman into a private room for the interview after her appointment. While waiting for study participants, interviewers reviewed clinic protocols, observed the clinical routines, and observed the basic layout of the building space and flow of clients. Ninety percent of eligible women agreed to participate in the Phase I interviews.

2.2.2 Phase I Interviews

A topic guide (Appendix 1) was developed to guide the interview process. In addition to collecting background information (e.g., age, ethnicity, marital status, etc.), the guide included questions related to the woman’s experience with HIV counseling and testing, such as:

- Use of ANC services;
- HIV testing experience at ANC clinic;
- Reasons for accepting or refusing the HIV test, and receiving or not receiving the results;
- Disclosure of test results; and
- General knowledge of HIV/AIDS and prevention.

Each interview lasted about 15 minutes and yielded an average of five to seven typed pages.

A total of 68 interviews were conducted in April and May, 2005. The topic guide was pilot-tested with 23 women during the first two weeks of data collection and then revised to include questions about why some women initially declined but later accepted the HIV test, as well as more detailed questions about HIV knowledge and participants' background information. Women interviewed with the original topic guide were not included in the final analysis. In addition, transcripts from four women were excluded because they did not contain answers to all of the essential questions. Thus, 41 interviews conducted with the revised topic guide were included in the final analysis.

<u>Table 1 Phase I participants</u>	
ANC clinic	Number of participants
Site 1	15
Site 2	13
Site 3	13
Total	41

2.3 Phase II

2.3.1 Phase II Recruitment

All women whose names appeared in the PMTCT log books at five ANC clinics between April 2004 and May 2005 were included in the sampling pool. The overall sample target was 15 women who tested HIV positive and received a complete dose of nevirapine (both mother and baby received a dose) and 15 women who tested HIV positive and did not receive a complete dose of nevirapine (either the mother, the baby, or both did not receive nevirapine, as determined by reviewing the hospital labor and delivery ward's PMTCT log book). Of interest, nine of the 34 women who tested HIV positive at ANC clinics and delivered at the hospital were not recorded in the hospital PMTCT logs; data from these nine women are included in the analysis.

An additional 15 women who tested HIV negative and matched 15 of the 30 HIV-infected women on age, parity, clinic and date of first ANC appointment were recruited to control for differences with regard to treatment, i.e., to determine if HIV-infected women were stigmatized/discriminated against based on their status. Women were matched by age and parity because women who are having their first baby have a different set of experiences upon which to draw and less family responsibilities, both of which could affect clinic attendance. Women were

also matched by clinic and date of first ANC visit to ensure that the woman had attended the clinic and because clinic practice can change over time.

In the initial recruitment period, women who received a complete dose of nevirapine were being recruited more rapidly than those women who did not receive a complete dose of nevirapine. Therefore, the study was expanded to include women from two additional ANC clinics in order to recruit at least 15 women who did not receive a complete dose of nevirapine.

Recruitment of women for Phase II occurred outside of clinic hours, at the woman's home. Recruiters used a screening instrument containing a short description of the PMTCT study as well as some simple questions to confirm that the woman had delivered a baby within the study time frame and that she had attended an ANC clinic. Recruiters were instructed to tell the woman about the HIV-specific nature of the questions only if the conversation was private. The recruiter would then ask the woman whether she would be interested in meeting with an interviewer at a convenient time and location of her choosing. Options for the interview location included the woman's home, the project office, or the health center. Recruiters were also instructed to try to visit each woman in the sample in the order that they occurred on the list that was developed from review of the PMTCT log book, to ensure a consistent sampling strategy. Recruiters were told to provide written notes in cases where they were unable to find women on the sampling list or when women refused to be part of the study. Women gave a variety of reasons for declining to participate in the study. Some said they had not disclosed their HIV status to family members and were nervous that their status would be discovered. Some said they did not have time because of work and family schedules. Other women simply refused without explanation. Seventy percent of eligible women agreed to participate in the Phase II interviews.

2.3.2 Phase II Interviews

A topic guide (Appendix 2) was developed to guide the Phase II interview process. In addition to collecting information on the same topics as in Phase I, the following topics were also included:

- Relationship history
- HIV test and results disclosure
- Birth plan
- Birth story
- Hospital experience
- Receipt of nevirapine by woman and baby (asked only of HIV-infected women)

Most of the women recruited for the study chose to be interviewed at the health center, telling recruiters that they did not feel comfortable being interviewed at home because of the risk that others might hear discussion of the woman's HIV status. In these cases, the Project Manager or one of the interviewers would meet the participant at the designated date and time in the waiting room of the health center. As in Phase I, the interview always took place in a private room. Before beginning the session, the interviewer reviewed the purpose of the study, explaining to the woman that she could refuse to answer questions or could end the interview at any time. The interviewer also reviewed the consent form in detail, reading the text to the participant and asking for a signature to confirm that she agreed to the interview and taping of the interview. At this point, the interviewer would explain that at the conclusion of the interview, the woman

would receive compensation for any transportation costs incurred in coming to the interview site (approximately \$1000 Guyanese dollars, which is equivalent to \$5 US dollars).

The Phase II interview guide was pilot-tested and revised during late April 2005. Analysis is based on data collected from 48 participants.⁵ Most participants were interviewed once. Follow-up interviews were conducted with 16 of these participants to finish discussing topics not covered in the initial interview, to clarify events, and to verify the consistency of answers. Each interview lasted 1–2.5 hours and yielded an average of 20 typed pages.

Table 2 shows the number of Phase II participants interviewed at each clinic.

<u>Table 2 Phase II participants by HIV status and receipt of dose of ARV prophylaxis</u>				
ANC clinic	HIV-positive participants		HIV-negative participants ³	Total
	Received complete dose ¹	Did not receive complete dose ²		
Site 1	9	4	4	17
Site 2	4	2	3	9
Site 3	5	3	3	11
Site 4	3	0	2	5
Site 5	0	3	2	5
Other	0	1	0	1
Total	21	13	14	48

¹ Complete dose means that the mother received nevirapine before delivery and the baby received nevirapine within 72 hours after birth.
² Either the mother or baby or both did not receive nevirapine.
³ Women who tested HIV negative did not require nevirapine.

2.4 Hiring and Training of Staff

2.4.1 Hiring

Three nurses and/or social workers who worked at one or more of the five study sites were hired as recruiters. They were chosen because not only did their work involve access to medical records, but they were also familiar with the neighborhoods in which clients lived and, in many cases, had already established a rapport with clients. In addition, three persons were hired to conduct and transcribe the interviews, and another three part-time transcribers were hired. All of

⁵ Data were collected from a total of 54 women. Data from seven participant interviews did not meet the study criteria because the women either attended a different ANC site (not one of the five study sites) or they did not attend the clinic during the study period. Six of these women were excluded from the analysis. The other woman did not receive a complete dose of nevirapine at the hospital, and because of the difficulty in recruiting women for this study group, her data were included in the final analysis even though she attended a different clinic for ANC.

the interviewers had prior experience working on HIV projects; one was trained as a nurse and the other two had worked as HIV counselors.

2.4.2 Training

The Project Manager met individually with each of the three recruiters on three separate occasions for one hour each time. In the first meeting, the Project Manager reviewed the documents, protocols, and procedures. In the second meeting, the Project Manager discussed the importance of maintaining confidentiality for the potential participants, as well as strategies to maintain privacy and avoid coercing clients into participating in the study. All recruiters were required to sign a Statement of Confidentiality. In the third meeting, the Project Manager reviewed the PMTCT log books with the recruiters, describing in detail the criteria for selecting potential participants.

The Project Manager also conducted a five-day training for the interviewers and transcribers. The first three days of training took place in the project office and included a lecture about the history of PMTCT services in Guyana, discussion of the study's goals and objectives, an in-depth review of ethical issues, instructions in interview techniques and the informed consent process, and a review of the questions in the topic guides for both phases of the study. The last two days of the training were attended by the interviewers and included role-playing exercises in which they practiced interviewing each other and the Project Manager using the topic guides. They were also instructed in the use of the tape recorder and transcribing machines.

Once the study began for Phase I, the Project Manager supervised the interviewers' first three interviews with clients and provided constructive feedback after each interview. The same process was repeated for the one interviewer who conducted the Phase II interviews.

2.5 Description of Study Participants

A total of 89 women were included in this study. All 89 study participants are described below, according to their background characteristics.

The age range of participants from both phases was as follows:

15–19 years	11
20–24 years	27
25–29 years	26
30–34 years	13
35–39 years	10
40–44 years	2
Total	89

Most women identified themselves as Afro-Guyanese (or negro) or mixed ethnicity:

Afro-Guyanese	46
Mixed	30
Indo-Guyanese	2
Amerindian	2
Unknown	9
Total	89

Most women described their marital status as single, followed by common-law (also called “living home”) and married:

Visiting/single	34
Common law or “living-home”	35
Married	12
Divorced	3
Unknown	5
Total	89

Women were also asked to describe how much education they had received:

Some secondary education	36
Finished secondary education	25
Some primary school	3
Finished primary school	10
No education	3
Tertiary school or higher education	6
No answer	6

Most women in the study had some secondary education, which is similar to the general population (71% of the population of women age 15–49). However, about half of the participants were of African descent (versus 30% of the general population), and women participating in this study were much more likely to be single or living with their partners, rather than married, whereas about 40% of women age 15–49 in the general population of Guyana are married.

Analysis of the data began in August and concluded in December 2005 when drafts of the report were circulated for review.

CHAPTER 3

WOMEN'S UNDERSTANDING AND USE OF HIV TESTING DURING ROUTINE ANC

This chapter describes ANC routines and the HIV testing process that is integrated into the clinic's general screening process. It describes women's views of ANC services and clinic attendance, as well as their history of HIV testing experiences. This information provides a context for understanding what women said about their recent HIV testing experiences during ANC, including: what they said about counseling, why they accepted or declined an HIV test, whether they felt the HIV test was voluntary, and whether and when they received results.

3.1 ANC Clinic Routines

Nurses at ANC clinics recommend that pregnant women first come to the ANC clinic in the first 12 weeks of gestation, followed by monthly visits up to 28 weeks, bi-weekly visits from 28 to 32 weeks, and weekly visits from 32 weeks until delivery. Prior to each ANC clinic session, women in the waiting room are assembled and receive a review of general health issues such as: nutrition, exercise, grooming, and proper behavior during pregnancy; how to recognize and respond to labor pains; and how to get appropriate postnatal care. Nurses also use this time to orient women who are visiting for the first time for a new pregnancy, explaining how HIV can be passed from mother to child and describing the interventions available to prevent this from happening. During this group talk, some clinics hand out the HIV-testing consent form for mothers to read prior to meeting individually with a nurse or counselor.

During individual consultation with providers, first-time ANC visitors are offered a battery of screening tests, including blood tests for hemoglobin, blood type, sexually transmitted infections (VDRL for syphilis, HIV), a swab test for gonorrhea if deemed appropriate on physical exam, and a stool test for parasites. According to protocol, women should be individually counseled prior to the HIV test and given a chance to ask questions of the nurse or counselor. If a woman consents, she is asked to sign a permission form. An anonymous number system is used to identify blood samples and record and track HIV test results. This procedure is also explained to women during this consultation. If the client agrees to HIV testing, venous blood is drawn for HIV and other pregnancy screening tests and sent to the laboratory for analysis. Results are expected after two weeks (or more, depending on the location of the clinic). The client typically receives her HIV test results at her next monthly visit. Individual post-test counseling is also provided at that time. A second follow-up HIV test is conducted on everyone during the latter weeks of pregnancy—approximately three months after the first test—to identify cases of sero-conversion occurring during the three-month window period. PMTCT sites also offer couple and partner counseling and testing.

Women who test positive for HIV receive additional counseling and information on HIV and learn how to prevent transmission of HIV to their baby at delivery. Each woman is instructed about the anonymous code used to record on her ANC card whether she tested HIV positive or HIV negative. A woman attending ANC for the first time receives a new ANC card. Clinic appointments and the results of screening tests are recorded on this card. The woman is instructed to bring the ANC card to each appointment and to the hospital when she checks in for

delivery. Women testing positive for HIV are also told about infant feeding options. The nurses recommend two options to HIV-positive women: not to breastfeed at all or to rapidly wean her infant at 3 months of age.

Clinic staff maintain an ANC log book with names and addresses of all clinic attendees. They also keep a PMTCT log book that lists all the patients attending ANC clinic as well as the results of their screening tests, including the first and second HIV tests.

3.2 Women's General Views of ANC and Blood Screening Tests

To get a sense of whether women valued ANC and the blood screening process in this study, women were asked, "What did you find beneficial about antenatal care?" "How do you feel about the staff and services?" "Do you usually take all screening tests offered at the clinic?"

In response to the first question, women stated a wide variety of benefits of attending the ANC clinic, including learning basic care of baby and mother during pregnancy, labor, delivery, and the postpartum period. For example, one woman said:

They teach us how to take care of the baby and ourselves and what to eat after and during pregnancy. [53: HIV negative]⁶

Women spoke very appreciatively about the educational aspect of ANC care. One woman said:

You learn a lot because every time you come, you get a health talk. You would learn about pregnancy and what is going on inside of you. You would learn about AIDS and how you can prevent things from happening. And when you go in to get the baby, what they expect of you. [15: HIV positive]⁷

Many said that they appreciated being able to ask the nurses questions and get help solving problems. For example, one woman said:

Certain things you don't know, you could ask questions and the nurse could answer. When I was pregnant, I was feeling a lot of pain under my abdomen, a lot of pain. I used to tell the nurse about it before and ask questions. [58: HIV negative]

At least half of the women interviewed volunteered that they appreciated the emotional support they received from nurses and counselors at ANC clinics. Specifically, women mentioned the importance of being able to talk openly with the nurses about their problems, as well as the fact that they felt comfortable in the clinic. One woman put it this way:

Like if anything bothering you during your pregnancy, you could sit down and talk to them and they would listen. [50: HIV negative]

⁶ Individual women quoted in this report are identified by a different number (1 through 89) and by their HIV status.

⁷ Most women interviewed spoke non-standard English that varied by the region where they were raised. The original quotes are presented verbatim.

On the other hand, when asked how they felt in general about the staff and services at the clinic, and whether there was anything that might be improved, several women (9) indicated that nurses were not always respectful. One woman mentioned that a nurse had been open about her disregard for the ANC clients and the need for prompt service:

One morning one of them [nurses] come in, and I just make a joke by saying you're late. She say, 'You don't pay me, the government pay me, and right now the government ain't here and I free to do as I like.' [49: HIV negative]

Another woman suggested particular nurses were less sympathetic than others:

They have this one particular nurse...I don't like the way she behaves...as if she don't want to touch you or if she don't want to talk to you...and if you ask her, she don't even comfort you...they would ask a question like, would it hurt or do I have to really get bore by that needle or so, she would say like once you is a woman you got to know about pain. [61: HIV negative]

One woman said that to receive good service during ANC it was important for patients at the clinic to cooperate with the nursing staff:

...we have to be patient with them, and we have to cooperate with them. If we cooperate with they, they would cooperate with we. If we don't cooperate they wouldn't cooperate with we. [53: HIV negative]

Other respondents said that some of the nursing staff are moody, which at times affected their interactions with patients:

When you come sometime, and say good morning, they wouldn't answer you, they mouth long. And if they tell you do something and you don't understand, they come out and say all kinds of things...I think they should work on their people skills. [64: HIV negative]

A large majority of women (80/89) said that they usually take all the blood screening tests offered at the clinic because the medical staff recommends them. One woman said:

Yes [I take them all]. I mean they are the doctors. They know what's best. [1: HIV positive]

3.3 Women's Reported ANC Attendance

To get a sense of women's use of ANC services, study participants were asked how many months pregnant they were when they came to clinic for their first ANC appointment for their most recent pregnancy, and whether they attended ANC clinic appointments regularly.

Although these numbers are not nationally representative, they do provide some idea of the number of opportunities clinic staff have for providing HIV testing and counseling services. Half of the women (44) interviewed said that they began attending ANC during their second trimester of pregnancy, and fewer (33) said they began during their first trimester. A small but significant number (8) said they began attending ANC during their third trimester of pregnancy.

First trimester	37
Second trimester	44
Third trimester	8
Total	89

The majority of women also said that they adhered to their ANC appointment schedule throughout their pregnancies, usually mentioning that they came “once a month” at the beginning, then every “two weeks,” and then “weekly” at the end. Several women said they did not attend every single appointment, citing problems of daily life that interfered. One woman, who attended ANC clinic regularly during her last pregnancy, said it was more difficult to come to the clinic after she found out that she was HIV positive:

I notice like if I come to clinic and nobody don't tell me about it [HIV] I would find myself uplifted but if they ask me things [about HIV] ...when I go back home I would feel sick because I'm studying it. Even now I stay away from clinic sometimes because when I come like it's a stress. [12: HIV positive]

3.4 HIV Counseling and Testing

All participants were asked whether they knew they would be offered an HIV test when they came for ANC, whether they were counseled, and if so, how. The majority of women (64) said they knew before they came that they would be offered the test at the clinic. They said they knew either because they had attended a PMTCT clinic for a previous pregnancy or because they had been told by a friend or relative who had recently been offered HIV testing at an ANC clinic during pregnancy.

Most participants stated that they did receive some form of HIV counseling before they took the HIV test. However, there were a few women who said that they did not receive any HIV counseling at all. Those who said they had received counseling were asked to describe their pre-test counseling experiences.

Several women said that they were made to feel comfortable or less anxious about the test, simply by talking with the counselors. One woman said:

I can't remember the exact things, but she spoke to me, she gave me strength. [69: HIV negative]

One woman who declined HIV testing initially said that her counselor met with her outside of clinic hours and encouraged her to accept an HIV test:

I meet the nurse like one time on the road and I decided to take her to have a drink at lunch and we talk about it. She tell me it would be better for me if I do the test so I could know, just in case I am positive it would give a better percent that the baby wouldn't be infected, so I said it's okay and I came in the next morning and I get the test. [8: HIV positive]

A few women mentioned specifically that they felt comfortable taking the test because they believed their HIV counseling and test results would be kept confidential. For example, one woman expressed comfort with the counselor as follows:

Number one, knowing that it's confidential and you speak to them, and they wouldn't go and tell anyone else. That was very comfortable. [61: HIV negative]

Another said:

They wouldn't go and carry your name outside. I say okay, it's no problem. [19: HIV positive]

A few women (4) said that the HIV education they received during pre-test counseling made them feel more comfortable interacting with people infected with the virus. One woman said:

First time, I used to tell myself, oh God, that person have HIV, you don't have to touch them. But I get to realize that how a person could have HIV and you could still be their friend, you could still eat from them, you can't catch HIV by eating with somebody, or sharing something. You know, I learnt a lot. [49: HIV negative]

A few women who tested HIV positive also mentioned that the counseling made them more comfortable interacting with their families in their homes because they understood that they could not pass the virus to family members through sharing cups or dishes, or by using the same toilet.

3.4.1 PMTCT Knowledge

Some women said that their decision to take an HIV test was directly affected by the counseling they received during ANC, because the counselors helped them realize that having the HIV test would improve the health of their babies by allowing them to prevent transmission of HIV.

When I come, you had to go through counseling. And we talk about HIV and they say, well, every mother should take a test. So that if you is HIV, they will treat the baby so the baby will not be HIV. [51: HIV negative]

The majority of the interviewed women stated directly or indirectly that HIV can be passed from mother to baby during pregnancy and birth, and it was clear that the women understood this concept. Many, however, gave vague responses when asked how and when this transmission might occur. Among those who offered more specific answers, most mentioned that it occurred during breast feeding, and fewer said during labor and delivery, or both.

3.4.2 Window Period

Although most women who participate in the clinics' PMTCT programs are tested twice during pregnancy, only a few women (6) said that they understood the concept of the window period. None of the women interviewed used the term "window period," but they indicated they understood that the HIV may not show up in the first test and that a second test must be conducted three to six months later.

You got to test back six months after...because sometime the virus in your system mightn't show up then, and it might show up after. [52: HIV negative]

3.4.3 Partner Testing

Several women (6) said that during pre-test counseling they were encouraged to bring their sexual partners into the clinic for HIV testing:

She say, 'How it make sense that you coming and take a test and your husband ain't coming and take a test? Both of you all should take this test.' Because is like if you could take a test now, and you faithful to him, but he ain't faithful to you, and he could go outside and bring it. And when you think you safe, you ain't safe. [51: HIV negative]

3.4.4 Women Who Did Not Receive Counseling

Ten participants (10/89) said they received partial or no HIV counseling prior to taking the HIV test. Among the women who said they didn't receive satisfactory counseling, one indicated that she did receive counseling about HIV related to the baby but not herself:

No, we didn't counsel about HIV...When they give you the counseling about the baby, they tell you about the HIV test, if you want to take it. And they fill out a form and they give you a paper to take the test and you go and take it. [36: HIV negative]

Other participants said that they received HIV counseling only in the form of group HIV education and did not receive individual counseling prior to being tested for HIV:

They didn't have much workers there you know, but all the people who went there that day, they stand up and talk to all of us at the same time and they talk to us and they tell us it leave up to us do it or not you know. It was our choice. [54: HIV negative]

Most of these participants replied that they were simply offered the choice of whether to accept HIV testing or not. One woman said:

[The nurses] told you about it and ask you if you want to do it, and I just say yes, and they send me to the room and just bore me and done. [86: HIV negative]

One woman who tested HIV positive at her first ANC visit said:

There was no counseling before or anything...the nurse came to me after going to the clinic and said you have to sign up these papers to do the blood test and that was it. I signed the documents and went to do it. [33: HIV positive]

3.5 Previous HIV Testing Experience

After discussing their recent HIV screening test at ANC, women were also asked whether they had ever had an HIV test before. Thirty-two participants said that they had been tested for HIV before their recent pregnancy. Of those who tested HIV positive during ANC (34) for their recent pregnancy, 12 had tested HIV positive on a previous HIV test before they became pregnant. Table 4 shows previous HIV testing experience by result and by recent ANC test result.

<u>Table 4 Participants' reported history of HIV testing by recent ANC test result</u>			
	Tested positive at ANC	Tested negative at ANC	Total
Not tested before	22	34	56
Tested HIV negative before	0	20	20
Tested HIV positive before	12	0	12
Total	34	54	88
Note: Information was missing for one case.			

Those who said they received an HIV test prior to their most recent test said they had either been tested during ANC for a previous pregnancy, as part of an employment-related requirement (food handlers⁸ and police women), or because of illness in them or their partner. One woman said she was tested when donating blood for her mother's operation.

3.6 Reasons for Accepting HIV Test

When women were asked why they accepted the HIV test during ANC, they provided a variety of responses. Most of the responses can be grouped under one of three categories: 1) health-related reasons; 2) the test was being offered as a routine part of ANC; and 3) the woman believed she was at risk of HIV because of her or her partner's actions. While these reasons are listed according to the first response given, most women gave more than one reason for accepting an HIV test.

3.6.1 Health-related Reasons

Nearly half of the participants said they accepted an HIV test "to protect the baby" and/or themselves (45/89). Many indicated this by saying that they just wanted to "know," they just wanted to "be safe," or because it was the "right thing to do."

⁸ According to regulations, all food handlers in Guyana are tested for tuberculosis (TB). There may have been some confusion on the part of the two women who reported being tested for HIV as part of an employment-related test for a food handler's job. They may in fact have been tested for TB, not HIV; however, this cannot be confirmed by the data.

Most of these women, however, said specifically that they wanted to know whether they were HIV positive so that they would be able to take steps to protect their unborn babies:

*[Counselor] say that if I get it, I could pass it to the baby, but if I get tested and I come out positive, they could give me something so the baby won't get it. So that is why I do it now...I have to put aside my fear and do it to protect my child.
[55: HIV negative]*

Besides saying they wanted to “protect their babies,” some women said they were concerned about their own health as well. One woman said:

I just want to know what going on with me body. Is me body so I go and do the test. [65: HIV negative]

Some gave more specific health-related reasons. For example, one woman said that she wanted to know whether she was HIV positive so she could decide whether to have an abortion. One woman replied that she wanted to be tested so that she would have time to prepare herself mentally, in case she was HIV positive.

3.6.2 Test Was Free, Routine, or Compulsory

About one-third of the women (23) interviewed said they got the test because it was offered as part of ANC screening. For example, women said they “thought it was routine,” “there is no harm in doing it,” it was “free,” or they “never had the opportunity before.” The convenience of having the HIV test provided during routine care worked in favor of women taking the test. One woman put it this way:

*...if I just come out of the house just so to say I doing a HIV test, I might back down. But if I come to the clinic and the clinic giving you for free, I won't hesitate...if you pregnant and you coming to clinic and they offer you, its easy.
[50: HIV negative]*

Nine of the 12 women who had tested HIV positive one or more times before they became pregnant went along with the test passively, without telling the nurse or counselor that they had tested HIV positive before. One woman who tested HIV positive during her last pregnancy said:

*Even though I'd done it I didn't mind going through the process again.
[9: HIV positive]*

During her second HIV-positive pregnancy, one woman said she had not told the nurse she was tested for HIV before:

No I didn't tell the nurse. After I took the test then I sat the next time before the results come and I told her. [3: HIV positive]

Two others said they were required to do another HIV test anyway. And one woman said that she was told that she had to take a test every five or six months [31: HIV positive].

When asked directly “did you feel you could have refused the HIV test during antenatal care?” the vast majority of women (77) replied that they could have refused it had they really wanted to:

I know it was my choice. [12: HIV positive]

However, some women (9) were ambiguous in their answers, and it appeared that their decision was also based on other considerations. A few said they took the test because it was compulsory. One woman said:

[I took it] because the nurses said it was compulsory now for you to take an HIV test...she say it's compulsory because remember now babies are borning with HIV and we cannot know the status unless you take a test. [25: HIV positive]

One woman said she did not feel it was a choice, but rather:

I thought it was protocol.

But then added:

I'm not upset over the fact that I did it. [33: HIV positive]

Another participant made reference to the rules set forth by the clinic and said it was implied that HIV testing was something pregnant women were required to do in order to participate in the ANC program.

I wouldn't refuse, because you come here now, and you got to comply with their rules...Because remember, this is the first time you joining, so they need to take the test...They didn't say you had to, but I know that I have to, so I just sign without even really reading [the consent form]. [26: HIV negative]

Some other women said that while HIV testing was voluntary at the clinics, nurses at the clinic told them that the hospitals required HIV testing prior to delivering a baby. As a result, several women (3) said they chose to be tested during ANC visits at the clinics to avoid the mandatory testing later during delivery at the hospital. One thought she would be tested before discharge from the hospital:

You got to take the test, because when you go to the hospital, you cannot go home without being tested. All the blood test you have to take before being discharged from the Georgetown Hospital. [50: HIV negative]

Another said she thought the hospital staff would suspect she was HIV positive if they saw that she had no results on her clinic card:

I don't want to go into the hospital to get baby and when they look at my card, they see I refuse to do the test, and they would say I'm a possible victim [of HIV]. [64: HIV negative]

3.6.3 Coerced to Have Test

A few of the women's responses (6) suggested clinic staff coerced them to get the HIV test. When asked "When you came here at the clinic did they tell you or ask you?" One woman (as did a few others) responded:

They tell me I had to do it, so I did it. [23: HIV positive]

Another woman said that she was told she would be transferred to another clinic if she refused HIV testing:

...they tell us that if we don't take the test, that they would transfer us to another clinic...I didn't want to get transfer, because I like it here. [55: HIV negative]

One woman said her blood was tested for HIV at the laboratory without her consent and it was only afterwards, when they told her the results, that she realized an HIV test had been performed.

3.6.4 Believed They Were at Risk

A significant number of women (11) said specifically that they took the test because they thought they were at risk from their partner's sexual activities:

I'm single...I don't wild about myself and I had my child father and I know he had his children mother and I know he used to play games so I really can't tell. I can't swear that things can't happen because you would be right in your house and things come to you. [34: HIV positive]

All of the women interviewed were asked how HIV is spread. The majority answered "sex," "unprotected sex," or "sexing;" a few added oral sex as a risky behavior for HIV transmission. Quite a few women also cited the sharing of needles or getting injections or blood transfusions as a mode of transmission. Women's responses made it clear that there was widespread understanding that HIV is a sexually transmitted infection.

Some participants responded that, in general, women should be tested for HIV because of men's proclivities to engaging in sex with multiple partners. On the other hand, some women admitted to having multiple sex partners themselves, to having gone outside of their primary sexual relationships. Others simply said that they were having unprotected sex in their current relationships. Finally, one woman said she wanted to prove to her partner that she was negative.

3.6.5 Hoped for a Change in Status

Three of the women who had tested HIV positive prior to pregnancy said that they took the test because they thought that their HIV status might have changed from positive to negative. One said she thought this because her CD4 count had improved, while the other two said they had prayed and wished for it:

To tell you the truth the reasons I took the test was because I thought it might come up negative. [10: HIV positive]

3.6.6 Wanted to Know Why Previous Baby Died

Another HIV-positive woman wanted to know why her baby had died after a previous pregnancy.

3.7 Women Who Declined the HIV Test

The PMTCT log book showed that the vast majority of women who attend these ANC sites are tested for HIV during ANC, usually on their first ANC visit. A small but substantial number, however, did not agree to an HIV test initially; by the end of their care, however, they agreed to the HIV test. Out of the 89 women we interviewed, only two were never tested for HIV during ANC.

Seven participants said that they initially refused HIV testing when it was offered to them. Of these seven women, five changed their minds and decided to accept an HIV test during their ANC. The five women who eventually were tested for HIV said they initially refused for the following reasons: two women felt they were not at risk for HIV infection because they were in a monogamous sexual relationship; another said she was afraid of getting a positive HIV test result; two others said they wanted to take time to think about it first; and another said she had taken the test during her last pregnancy and had not “played out” since then. These women said they talked the test over with another person after being offered an HIV test at ANC—either their partner, mother, and/or nurse—and were convinced by the other person to take it.

The two women who were not tested at all during ANC both said that because of their partner’s and/or her own sexual activities, they were afraid they were positive and did not take the test because they did not want to know the result.

3.8 Women Who Received the Results of the HIV Test

The majority of women interviewed for this study said that they received the results of their first HIV test at the clinic before delivering their babies. Among the women who received their results from a health care provider, most (76) responded that they received them during the ANC clinic visit that followed the HIV test. For some women, this meant they received their results one month after their initial HIV test (51). Others were attending the clinic more frequently and said they received their results one or two weeks after the initial HIV test (25). A few women had to wait two to three months for their test results (6) or said they never did receive the results of their HIV test from a health care provider (5).

The five respondents who said that they never received any HIV test result before delivering their baby said the following. One woman said that she discovered her results were recorded only after looking at her clinic card, but that no one from the clinic sat down to explain the results to her. Another woman said that she was asked to do a “repeat test,” but never received the results from the first test she had taken three months earlier. One woman said she was transferred to Georgetown ANC before she took a test at the community ANC, but did not receive the results of the Georgetown ANC test until after giving birth:

It takes long to reach back sometimes...then I had to go down for it and when I went down they were on lunch and I sent my mother back for it but she didn't get it. [54: HIV negative]

Another two women started attending ANC at six months' gestation but delivered prematurely, and therefore received their HIV results after delivery.

Although not all women were asked whether they accepted and then received the results of the second HIV test taken later in pregnancy, at least five women mentioned that they had taken the test and not received the results.

3.8.1 Confirmation Test

The majority of women who tested HIV positive for the first time during ANC went to other health facilities to be retested to confirm the results. These confirmatory tests were usually performed in private laboratories. In the most extreme case, one woman said she had received five HIV tests, and her husband seven tests, following a positive result during ANC screening.

3.9 Chapter Summary

The women interviewed for this study were asked a range of questions about their experiences with ANC and HIV testing during their most recent pregnancy. The following are some conclusions about how HIV testing offered through ANC clinics fits into women's usual ANC practices, women's experience of the HIV testing process, and why they do or do not accept HIV testing.

Most participants said that they value ANC service provided through the study clinics, including the educational, diagnostic, problem-solving, and emotional support they receive from the staff. The identified drawbacks of ANC service included that the clinic staff sometimes asserted their authority with clinic attendees during clinic hours. Some criticism was focused on particular staff members who were said to be moody and unsympathetic to the difficulties of pregnancy and the medical procedures that women had to undergo.

Overall, women value ANC, and their use of ANC services reflects this. They said they usually began attending the clinic during their first or second trimester and attended most appointments according to schedule. A large majority of women (80) said they usually take all blood screening tests offered as part of ANC, and most (64) said they knew they would be offered an HIV screening test at ANC. Many (32) women had an HIV test before: 12 of the 32 women previously tested had tested HIV positive before they attended ANC.

The number of women who became pregnant despite knowing they were HIV positive (12) suggests that family planning, although already offered as part of the service package, should be emphasized to ensure that women do have the option to prevent unwanted pregnancies.

Most women (79) said they had received some form of HIV counseling before taking the HIV test. Aspects women mentioned that they appreciated about the counseling included feeling comfortable talking to the counselors, who gave them strength to take the test (one counselor even provided counseling outside clinic hours, when requested). Those who said they were not

individually counseled reported that during busy periods, staff relied on group HIV counseling only.

Most women said it was their choice whether or not to take the HIV test (77). Some said it was voluntary within a system where HIV testing is reinforced more than once: “You got to take the test because when you go to the hospital, you cannot go home without being tested.” A few women (6) reported they were coerced into taking the test or tested without consent. One reported that all women at the ANC waiting area were told they must “get the HIV test or transfer to another clinic.”

The main reason women gave for accepting the HIV test was to know their HIV status so they could prevent transmitting it to their baby (44). The second most common reason was that the test was being offered through ANC; this made the test convenient, free, and routine, all of which women found appealing (22). Some women (11) said they took the test because they thought they were at risk from their partner’s or their own actions. A few women said they accepted the test because they were coerced by clinic staff (6). When women find out that they are HIV positive, most will undergo tests at other laboratories, usually private ones, to confirm the results. Many have more than one test.

A few women who tested HIV positive prior to their most recent pregnancy said they took the test because they thought they might come now have a negative test, either because their CD4 count was better or because they had prayed or wished for it. One woman took the test to see whether her previous child might have died because she was HIV positive.

Women have a basic understanding of the major ways in which HIV is transmitted: through unprotected sex, and vertically from mother to child. Still, women have only a very rudimentary idea of when and how the transmission occurs during pregnancy, labor, delivery, and the postpartum period. Few women understood the window period. This suggests that women might benefit from knowing more about the physiology of HIV transmission and how this physiology is related to the services they could use to prevent transmission, i.e., HIV testing twice, ARV prophylaxis to mother and baby, and counseling on alternative infant feeding.

Counseling women that HIV is not transmitted through casual contact, such as sharing cups, plates, or the toilet, was said to make both HIV-positive and HIV-negative women more comfortable interacting with others. One woman expressed the desire for counseling on how HIV affects the mother herself rather than just how HIV would affect the baby.

The majority of women attend ANC clinic frequently enough to receive HIV counseling and testing twice. A small but significant number of women who tested HIV positive (3/34), however, did not have even one HIV test result on their ANC cards at the time of delivery, even though they were tested: two women because they had not attended ANC more than once before having an early delivery, and one laboratory mix-up and retest that was not recorded until after delivery. At least 10 women who mentioned that they were tested twice reported not having received the test result of their second HIV test prior to delivery.

CHAPTER 4

HIV TEST AND RESULTS DISCLOSURE

This chapter describes whom women told about giving blood for an HIV test and whom they told about the results of the test, and their reactions. Women who tested HIV positive (34) told others about the results of their HIV test less often. We describe their experiences, identify the person they told, and outline the reasons they gave for not disclosing results to partners. We also describe the consequences of telling others about their HIV status as reported by women. This includes the general reaction of those told and whether disclosure of results initiated a change in their relationship or living situation.

4.1 Disclosure of Giving Blood for HIV Test at ANC

Study participants were asked, “Did you tell anyone you were tested for HIV after clinic?” Most women who had not tested HIV positive before their current pregnancy said they told at least one person, and many said they told more than one other person that they had been tested for HIV at ANC. Most said they told their partner they had been tested, although many said they had also told their mother, sibling, or other family members, and friends.

Only a few of the women said that they did not mention to anyone that they had given blood for an HIV test. When asked why they had not mentioned it to someone, the general answer was that they wanted to know the results first. One woman said:

No, I didn't want to tell anybody until I got the results...I wasn't sure. I was a little insecure about my relationship. [54: HIV negative]

Most of these participants said they felt comfortable discussing HIV testing with their male partners. A few women who initially refused an HIV test reported that their male partners encouraged them to take the test. One woman said:

Because he said it [HIV test] was nothing to worry about and wanted to know why I was frightened because he said you can't frighten, you have to take it. [57: HIV negative]

A few of the women who had tested HIV positive prior to their last pregnancy and who had not told their partners their HIV-positive test results before, said they also did not tell their partners about the results of their most recent ANC HIV test.

4.2 Disclosing HIV-negative Results

A large majority of the women who tested HIV negative told their partners or other family members about their results. According to these women, the reactions of partners ranged broadly, from indifference to pleasure: “nothing much,” “he didn't feel no way about it,” “he didn't say anything,” “he wasn't surprised,” “they were happy,” “they felt great,” or “he was glad.” A few said they did not tell their partners because they forgot.

4.2.1 Partner Testing

Although women said that nurses and counselors encouraged them to bring their partners in for an HIV test, most often they said their partner either did not come for testing or took the result of the woman's test as verification of their own HIV status. One woman said that when she asked her partner to come in for an HIV test he responded:

If you are negative he don't see why he should come. [54: HIV negative]

At least two women who tested HIV positive had the same experience. One of these had had two HIV-positive pregnancies. According to her, when she asked him to get an HIV test, he said:

*He done know about me and it don't make sense he go and find out.
[21: HIV positive]*

In both these cases, the man took his wife's HIV test result, either positive or negative, as evidence of his own status.

One woman tested HIV negative but positive for another STI during ANC, and the nurse, she said, insisted that she bring her husband to the clinic for STI testing. He tested HIV positive. With the knowledge that she was negative and he was positive, the woman stopped having sex with him, although they still live together she says, "for the sake of the children" [51: HIV negative].

4.3 Disclosing HIV-positive Status to Others

Most (27) of the 34 women who tested HIV positive at ANC said they told someone about the results of their HIV-positive test. Most women (21) who disclosed their HIV-positive test said they told their male partners, and many of these women also told other family members. Six women who tested HIV positive did not tell their partners of their HIV-positive status but did tell another family member. Seven women said they told no one about their HIV-positive test results.

4.3.1 General Reasons for Not Disclosing HIV-positive Status

The reasons women gave for not telling others about their HIV-positive status varied. Both the women who had disclosed their HIV status and those who had not cited the following general reason for not telling family members their HIV status.

Protecting the Vulnerable: Sick and Young

Some of the women (8) said they hesitated to tell parents because one or both were sick. One woman said she never told her mother, with whom she lives, because:

I didn't want her to take it on. [7: HIV positive]

"Taking it on" or "studying it" are terms women frequently use to describe thinking too much about one thing to the exclusion of everything else, i.e., worrying. One woman described it like this:

I see a lot of people when they find themselves sick they would take it on and study it. For instance they would study it and it would be like a child to them. [82: HIV negative]

As another woman described it, some people lack the capacity to handle bad news and are thus more vulnerable:

I don't think she (mother) will be able to, as I said about the capacity to take certain news. That's the reason why. [13: HIV positive]

This woman had the support of her husband and she added that she could protect her mother as long as she was able to bear it.

And I am bearing it right now so I don't think it's necessary to get anybody else involved. [13: HIV positive]

Another woman, however, who had not told her partner about her HIV status because she was afraid of physical violence, said she did tell her mother, who was diabetic. Here is how she described her “taking it on:”

Well, especially my mother, she is a sugar case right, she does take it on a lot. And right now she sugar gone to four hundred and something because she does take it on a lot. She does cry a lot. [14: HIV positive]

One of the things she said her mother was worried about was what would happen to her daughter when the woman's husband found out. The mother was described as going in and out of denying her daughter's status.

She's still in the big 'might have it' and stuff like that. [14: HIV positive]

Some women gave multiple reasons for not wanting to tell family members about their HIV status. Besides worrying about her mother's health, she thought telling her might result in getting kicked out of the house.

She might get a nervous breakdown, and I might get kicked out of her house and three they might disown me like they did when they found out I got married. [17: HIV positive]

Another group of family members considered vulnerable and protected from disclosure of HIV status were the women's children. When asked whether her five children knew she was infected with HIV, one woman responded:

Well, you see, I say she [daughter] wouldn't understand, although she's nine or so but she wouldn't understand certain things right now. [19: HIV positive]

Another woman said she would feel uncomfortable telling her eldest son, who is 21 years old, because:

He might go away from home...because he might not be able to take it. When I told my daughter she could not take it. She started crying. [4: HIV positive]

Yet another woman, a single mother of five, reflected on her reasons for not telling her children:

If they [children ages 1 to 10] know that I'm HIV positive and then they hear that you die from it, they're going to take it on and then they might not want to do their school work, and so, they might get sick or who knows what will happen to them so I can't let them know, I won't let them know. [18: HIV positive]

Not Close to Family Members

A different reason cited by five women for not telling family members was that they were not close to them. One woman said her family often fights:

But everybody will be disappointed because I'm the last and I don't know what will happen because my family is very ignorant right...they like fight and they like curse-out. That is why I move from up there and come to town. Cause I don't want to be in that position at all. [2: HIV positive]

Another woman said her family did not treat her well because of her physical features.

Since I was small my mother is Amerindian and Indian and my four sisters have one father and he is mixed so they have nice hair...but you see I'm dark and they have color, so from small they never liked me they would treat me bad...[my mother] told me she doesn't like me...she said I'm too black. [12: HIV positive]

Fear of Rejection and Scorn

A substantial number of women said they would not tell certain family members their HIV status because of fear of rejection and scorn. One woman who told her partner her status said:

I didn't tell my aunts, my mom, my sisters and brothers...I feel they would be vex with me, they would scorn me and what's not but time to come I might have to tell them someday but to me right now I don't feel it's the time to tell them. [31: HIV positive]

The term “vex” was used often by women to describe someone getting angry.

4.3.2 Specific Reasons for Not Disclosing HIV-positive Status to Partner

The reasons given by the seven women who said they had not disclosed their HIV-positive status to their partner were of a more serious nature: fear of physical violence, fear of losing a place to live, or fear of losing a job. Some simply were no longer in contact with the partner. These women often gave multiple reasons (listed below) for not telling their partners; we analyzed them by the first answer given. Some women (6) had told another family member their HIV status, and some (7) had told no one at all. We analyzed the responses of these 13 women together below, according to the main reason they gave for not disclosing their HIV-positive status to their partners.

Fear of Physical Violence

Four women said that they did not tell their partners because they were afraid the partner might hurt them. Three of these women thought they might have infected their partner. One of these women said:

I'm so [nervous], because actually, you got to say is me, I give it to him. I didn't know right, I didn't know that I had it.

She said she is afraid of her husband's temper:

He has a very high temperature...I don't know what he would do...for instance, you know how it going now, people like murdering people and stuff like that you know. [14: HIV positive]

Another woman who also thought she might have infected her partner said she also feared being "beaten" or "killed." She tried to get her husband to come to the clinic for testing, rather than tell him her status.

I tell him to come to the clinic...tell him that the nurses want to see you at the clinic. He say he don't have time. So I said to myself is okay if you don't have time, do what you want to do. So he never come and check up, do a test or no...no, I did not [tell him my status]. [19: HIV positive]

One young woman, pregnant for the first time, was worried about telling her future husband about her test results. She said she does not know who gave it to whom:

I'm confused, I don't know what to think.

She speculated about asking her partner to go with her for an HIV test:

But what I'm thinking right, if I go to the private hospital and take I and my own is positive and his own is negative, what will happen? He will kill me. I don't know what he would do to me. [2: HIV positive]

Afraid of Being Put Out of the House

Three women responded that they might be put out of the house were they to tell their partner they tested positive. For example:

I feel if I tell him he might want me to move out with the children so I didn't tell him anything until I feel the right time meet I'm going to tell him. [31: HIV positive]

Another woman, who said she wanted to take another test to confirm her results, said that her in-laws, with whom she lived, were people who "own." She speculated about what might happen if they retested together:

I feel scared...I just can't believe I got that...but you know I want to do another test but I get nervous. [12: HIV positive]

She said that she just keeps postponing the test.

Afraid of Losing Job

Two women who said they told no one about their HIV-positive status said they were afraid that if it were generally known, they might lose their jobs. For example, one who works at a hospital where her husband also works has been worried that the doctors who treated her and also work at the hospital where she is employed might disclose her HIV-positive status in the work place:

I wouldn't like for them to chase me from the work site or anything...I still be frightened because all of them [doctors] know my husband. [14: HIV positive]

Feel Guilty

A woman who was sexually active with a much younger man said:

If I had known that at the time I wouldn't have been with him.... I said if they could get him to the hospital because I can't tell him, right. They must have some way to test him and if it shows positive then they must tell him and let him do what he got to do. So he could take care of himself more better. I can't tell him myself. [5: HIV positive]

No Longer with Partner, or Were Never Close

Three women said they did not tell their partners because they were no longer in contact with them or they had never been close. One said she had been with her boyfriend for only six months. Now, she said, they only greet each other on the street. She told her parents, cousin, and aunt, all of whom she says are "very much supportive" [11: HIV positive]. Another woman was having sex with a man to help support her children. They lost contact after she became pregnant.

4.3.3 Disclosure among Women Who Initially Did Not Disclose HIV-positive Status

There is some evidence to suggest that women who do not feel comfortable disclosing their HIV status may be more likely to do so once they become ill. One of the women who had tested HIV-positive several years before and had had at least two HIV-positive pregnancies did finally disclose her status to a friend. After being teased for losing so many babies (four of eight died) by her relatives, she said she finally told a friend about her status and situation:

After I started to get really sick I decided to open up...I feel much relieved because they said that I must not spread it around and I don't worry because my boy would say 'what she has, she didn't buy it.' [3: HIV positive]

Another participant said her mother was the only person to whom she told her positive status. She said her mother reassured her that:

The only time she would tell them [others] is if I get really sick. [32: HIV positive]

4.4 Consequences of Disclosing HIV-positive Results to Others

Below are women's descriptions of the consequences of disclosing their HIV status to partners and family members. Consequences include the general reaction of those told, e.g., expressing support, denial, grief, disbelief, blame. Disclosure of results may also have initiated a change in their living situation or relationship. Twenty-one women said they told their partners and often family members; six told a family member only (but not their partners). Seven women told no one and therefore the consequences have yet to occur.

4.4.1 Support

Twelve of the women we interviewed said that they had told either partners, family members, or both, and they felt that they received support as a result. Two women whose partners also tested HIV positive said the diagnosis had brought them closer to their partners. One woman said:

*At first [he was upset] but now we even living better than before...it helped me.
[10: HIV positive]*

Another woman, whose husband was sick with AIDS at the time she was diagnosed, said she told her sister first, and then told her aunt. The family has been supportive of her and she says she is able to help educate her friends without disclosing her status. She said:

I would sit [with friends], I won't tell them naturally that I have AIDS but I would give them advice. Because I was telling my sister and her friend don't do this or that [to avoid AIDS]. [27: HIV positive]

Another not only told her family living in Guyana but also her father in Barbados; he now sends her medicine.

Contagion and the Limits of Support

A significant number of women said they knew family members accepted them regardless of their HIV status because they were willing to share intimate objects with the women. One woman who told her mother about her HIV-positive status said:

My mother would come and would cook and she would eat and sometimes if I leave back drink in a cup she would drink my drink. [32: HIV positive]

Another woman contrasted the supportive treatment she received from her family with the unsupportive treatment of a friend by her family:

They don't like her and they don't even eat after her or want to do things for her. My mother eats after me. That is not a problem. [23: HIV positive]

Another woman described the support and care from her family:

*Well they tell me, don't take it on and just eat good and live a normal life.
[29 HIV positive]*

Yet another woman said that although everyone should be treated as a human being, if you look sick, then the principles of sharing intimate items do not apply:

But if you looking bad, like you get plenty sores and so, you're suppose to be in the hospital. Not around people cause you know, something could catch. [2: HIV positive]

Rather than sharing and being with others, she says, one should isolate oneself from others so they do not contract any illness. She may be referring to other types of infectious diseases, such as yeast and skin infections, and respiratory infections to which HIV-infected people are susceptible.

4.4.2 Denial

Seven women described reactions to the HIV-positive test that suggested various ways that the family was in denial about their HIV status. One woman, for example, said she told her partner her status *before* they had a sexual relationship and lived together. She said that her partner “doesn’t believe” that she “has it,” since she’s not sick. When asked whether she understands the risk she is putting him at by having unprotected sex she said:

I've begged that man to use condoms he doesn't want to use...I don't know how to get him to use condoms. [9: HIV positive]

She said her HIV-positive status was somehow leaked to her mother, who told everybody.

First my mother used to behave a little funny. And when she tells people they would tell someone else. But in my case people don't know what to believe because I'm getting fatter all the time. [9: HIV positive]

Others mentioned the belief that looking healthy and/or being fat meant you do not have HIV and seemed to bolster the ability to deny being infected. Another participant also said that her husband does not believe that she is infected with HIV:

He believes, but sometimes he would tell me that he don't think because I look good but he know I take treatment... He took two tests but he never went for the results. He doesn't want to know and plus he's getting big and strong... When he gets a cold or so, I would give him my tablets that they give me to use. [3: HIV positive]

Yet another woman seemed to be in denial herself about where she might have contracted HIV. She reported that her husband was supportive even though he told her his tests for employment at Georgetown Hospital were negative:

Well he was supportive. And at least he was shocked right. Until now he still tries to cheer me up, and understanding which in I find that surprising because some men would have gone they way already and leave me. [12: HIV positive]

She rejected the idea that she might have become infected by the father of her first two children or her current husband. When asked how she thinks she could have gotten it, she said:

That is puzzling me. I said the only way I could have gotten it was through my sister because at that time I was the only girl in the family and I used to do all the runnings at the hospital and I didn't know well then you had to use gloves. So I was using my hands to tidy up, so that is the only possibility. [12: HIV positive]

Another woman said she had only had one sexual partner and she “can’t believe it” [7: HIV positive].

Yes I told him [partner] because I told him that he has to come here and do the test also...he told me that he is working and can't get the time to come because at that time he was working in Berbice. He told me that he would come to town a day and come and get the test but he never came.

She added:

[I'm] waiting on him because I said we'll go privately and do it because I'm still saying that it's not true...I have to see for myself somebody draw this blood and test it right there...so I need to see the blood drawn out of me and put in front my face and test it right in front of me. [7: HIV positive]

Another woman described how she ran out of the ANC clinic when she learned she was HIV positive:

She was looking for the paper and I see it and then she tell me that they find HIV in me blood and I say what, and I just run out the door... I just stopped coming to clinic till I don get baby...

Although clinic staff tried to contact her at home by telephone many times, she said:

I used to tell them I'm gone. [16: HIV positive]

Her partner of 13 years, father of all her three children, reacted as follows:

He didn't answer, he just walk and go out, we ent talk like about three months... I got it from no where else, he know where he get it from. Me and he did break up when me son dead for six months. [16: HIV positive]

A single mother of five just experienced her first HIV-positive pregnancy. She had had at least two previous abortions and wanted to abort this pregnancy but it was too far along. She said:

I don't believe them [results] because I believe in my Lord and I know he [God] could cure anything so somehow I don't get the feeling about it or whatever the case may be so I don't really take it and make it a study. I just let it ride like a normal story or whatever the case may be. I don't really take it on. [34: HIV positive]

She says her only problem is how to raise five children as a single parent.

4.4.3 Feeling Blame or Grief

Three women described feeling blamed by relatives or grief. One young woman, who said she had worked in the bush as a prostitute for a while, was open with her partner and family about her HIV-positive status.

Two women who reported telling their partner and most family members about their HIV-positive status said that although everyone knew, they did not discuss it openly. One of the women had a two-year-old son who had tested HIV positive and an infant whose status is unknown. She said she tested HIV negative for the previous pregnancy but the child tested HIV positive at clinic follow-up visits. She said she told the father of her two youngest children:

Well I cried and he cried.

She said she told her mother and other family members as well, but they do not talk about it much now.

Everybody just cries, nobody wants to hear about it... I feel really bad when I leave this clinic, I would feel miserable whole day until finally I would laugh and catch back myself. [24: HIV positive]

4.4.4 Break in Relationship and/or Change in Living Situation

Five women said that their relationship broke up and/or their living situation changed after they found out they tested HIV positive.

One woman said she told the father of both of her children, who currently lives in New York:

After I found the results I was suspicious of him. I told him I had to tell him something, he was in America, and he came back like a week later and I thought to myself that he knew what was going on...the first thing he asked me was if it was something to do with AIDS. [33: HIV positive]

This participant said that he encouraged her to abort and tried to deny paternity to her mother. She lives with her mother and sister now, but has not disclosed her status to them.

A couple of her partners had died, perhaps from AIDS. She had tested HIV positive years before but said she did not really believe it. She said when she tested HIV positive with her last pregnancy she told her partner, with whom she had been for several pregnancies. One woman had lost at least three babies prior to our interview. When she told him, "he went away." Now she lives by herself with the baby.

Another young woman told only her partner. She left him and started over by herself because, she said:

I don't want him no more, because he cost me my whole life, there's nothing could heal me...no he wouldn't go [for a test]...he say he don't want to know. [1: HIV positive]

Yet another young woman married against her parent's advice. She described a very rough childhood that included having been kicked out of her mother's and stepfather's house at the age of 14. She described her relationship with her husband as troubled. They had both gone together to be tested for HIV at Lifeline (a non-governmental organization) and they had discordant results; hers was HIV positive and his HIV negative. After that, she said, they broke up and she moved back to live with her mother and stepfather.

Another very young woman, experiencing her first pregnancy, said she told the father of the baby; they cried and took more tests. Eventually they broke up, according to the woman, because of "hitting" some months after the child was born. She now lives with her aunt. She reflected on the experience, saying she would have had an abortion had she known in time that she was HIV positive.

4.5 Going Public

All the women interviewed said they would not tell anyone outside of their family about their HIV status because they feared they would be shunned, or worse. One woman said:

I don't want nobody to look at me funny way, you know, that is why [I would not tell anyone else]. [10: HIV positive]

Another said she has not discussed the results of her test with anyone else because it would be more difficult to get a job:

Well after people realize you have this HIV they try to shun you out they treat you different than other people, it's hard for you to have a job and these sorts of things and some people don't even want you around them. So it's very hard. [12: HIV positive]

She said that if she were to talk about it outside of her family, people would gossip:

Yes. They watch and talk about you and make you feel bad, that is why I don't tell anybody my business. I just keep to me, my mother, my children and God. [24: HIV positive]

One woman reported that such a disclosure could result in getting hit on the street:

Yeah, and I know somebody who got it and people does scorn them and even pelt them when them passing. [16: HIV positive]

4.6 Chapter Summary

All the women interviewed for this study were asked a range of questions about the HIV test, test result disclosure, and the reactions of those they told. Their experiences are summarized below.

A large majority of women told others they had been tested for HIV at ANC. Those who did not tell either forgot or were waiting for results, or had tested HIV positive before and were not willing to disclose.

Most women (27/34) who tested HIV positive told someone they were positive. Twelve women informed their partner only, nine informed their partner and family, and six told a family member only. No woman told anyone outside of their family, for fear of rejection, scorn, and attack, with the exception of one woman who told a church friend.

The reasons given by seven women who told no one of their HIV-positive status included: fear of physical violence from partner (3); fear of being put out of the house (3); and fear of losing a job (1). Those who thought they might be assaulted by their partner also thought that they might have infected their partner. The reasons given by women for not telling family members included: a desire to protect the vulnerable member, lack of closeness to family members, and fear of rejection and scorn.

There is some evidence that women who keep their HIV status a secret for a while finally disclose when they become sick, need more support, and are no longer able to hide their HIV status.

Consequences for those women who told about their HIV status included: receiving support; experiencing grief, denial, or blame; and breaking up of relationship and/or living situation. Family members demonstrated acceptance of the HIV-infected person by sharing intimate items, such as cups, plates, and toilets, or, conversely, lack of support by not doing so.

Throughout the report there is the theme that if a person appears ill from HIV or AIDS—especially if s/he has skin problems—the person is assumed to be “contagious.” This assumption is used to exclude from normal social contact those sufferers of HIV/AIDS who appear sick. Conversely, without these “contagious” signs, an HIV-infected person will have a ready alibi to deny infection.

Although the male partners sometimes support women’s decisions to be tested for HIV during ANC, they do not usually come to the clinics for testing themselves. Some women said that their male partners took the women’s test results, positive or negative, as a reflection of their own HIV status and did not feel the need to get tested.

CHAPTER 5

WOMEN’S DELIVERY EXPERIENCES AND WHY WOMEN TESTING HIV POSITIVE DURING ANC DID OR DID NOT RECEIVE NEVIRAPINE AT DELIVERY

This chapter is based on analysis of interviews with 48 women about their birth and hospitalization experiences during their most recent pregnancy and delivery. It also describes the labor and delivery setting and the process of checking in to the labor and delivery unit at Georgetown Public Hospital Corporation. All the women were asked about their delivery plans, the signs used to determine onset of labor, getting to the hospital, and giving birth, and their views of the services. These basic aspects of women’s usual labor and delivery practice—for example, how they determine when to go to the hospital for delivery and their reported experience while hospitalized during a recent pregnancy—provide a general picture of how women use and view these services, regardless of HIV status.

Of the 48 women interviewed about their labor and delivery experiences, 34 had tested HIV positive and 14 HIV negative. Of the 34 HIV-infected women, 21 received a complete dose of nevirapine (i.e., both mother and baby receive the appropriate dose of nevirapine) and 13 did not receive a complete dose (i.e., either mother or baby or both did not receive the appropriate dose of nevirapine)⁹ at the time of delivery. These women were asked specific questions about whether they knew they should receive a nevirapine tablet prior to delivery, whether and when they received an oral dose of nevirapine, and when and how the baby received a dose. Both the ANC clinic PMTCT log book and the hospital PMTCT log book report whether a woman testing HIV positive and her baby received a dose of prophylactic nevirapine at delivery.

The chapter also explores women’s critiques of their hospital experiences and reports of problems related to being hospitalized as an HIV-infected person.

5.1 Georgetown Labor and Delivery Setting and Clinical Routines

The labor and delivery and postpartum wards are located on the second and third floors of the south block of Georgetown Hospital. Women who come to the hospital in labor go directly to the labor and delivery area to check in with the staff. Women are instructed to bring their ANC cards to the hospital when they check in to the labor and delivery unit. They are asked to fill out a form with needed admission information. Once they are checked in, women are free to walk about or sit on the wooden benches provided in the laboring area until a staff member calls them to be examined. Depending on the time of day, a family member accompanying the woman may or may not accompany her to the ward. In general, the visiting hours for the hospital are from 6-6:30 am and from 2-6 pm. These hours are strictly followed. Visitors are not allowed in the laboring area, which sometimes includes the waiting room.

The major way that medical information about a woman’s care (including HIV screening test results) passes among the ANC clinic staff is via the ANC card. Blood screening test results performed at the ANC clinic are recorded on the card, including whether the woman tested HIV positive or negative. A code number is used for this purpose, and its meaning is not obvious to

⁹ After examining all the data, two of the 13 cases had incomplete or conflicting data about whether the woman received nevirapine or not. One of the two cases is presented in the report.

anyone but the staff. The ANC clinic also circulates a list of pregnant women who tested HIV positive during ANC. The nursing supervisor of the labor and delivery unit uses this list to check the HIV status of women who do not present their ANC cards upon admission. Staff members construct a patient chart to be used during hospitalization, which includes admitting information, the ANC card, and any other available information. This chart is kept with the patient at the end of her bed.

When the receiving nurse deems it appropriate, an initial physical assessment is conducted. Once the woman is assessed to be about to deliver, she is brought to the delivery suite, where labor and delivery nurses assist her. Some women go straight to the delivery room, depending on how close they are to delivering their baby. They may sometimes be admitted to an antenatal unit bed located on the same floor.

ARV prophylaxis is prescribed for all HIV-infected women and their newborns. This consists of a single oral dose of nevirapine to be administered by hospital staff early in labor, and a single dose of nevirapine syrup to be administered to the newborn within 72 hours after birth. Most women reported receiving their dose of nevirapine in the delivery room. After the baby is born, the infant is taken for an examination; many receive nevirapine at that time.

The labor and delivery staff maintains a PMTCT log book of all HIV-positive women in labor presenting to the maternity ward staff. The name of the woman is recorded in this book, along with the date of delivery, whether the mother received nevirapine, and whether the baby received nevirapine. Sometimes notes are added to explain why a woman or baby did not receive prophylactic nevirapine. A note written to explain why one of the study participants did not receive nevirapine said, “Did not disclose; number not on card.”

5.2 Birth Stories: Planning, Signs of Labor, and Getting to the Hospital

When asked whether they had planned for delivery ahead of time, most women either did not respond to the question directly or responded with the story of how they got to hospital, suggesting that delivery planning, per se, does not concern them much.

When asked whether they had an explicit plan for delivery before going into labor, at least five women said they had “no plan” or were going to “wait” or “let it ride.” One woman responded:

I didn't have no plan...I just let it ride like that. [14: HIV positive]

Another said:

My family around so I didn't have to make no plans. [34: HIV positive]

It was clear from the birth stories, however, that all women knew where they were going to deliver, and that they planned to go when they experienced labor signs (described below). A few said they had a plan of who would take them to the hospital and how they would get there. One woman said:

My child father would take me. [40: HIV negative]

Another woman said she planned to stop work, had a bag packed and ready at the neighbor's house, and she took a taxi with a neighbor when she experienced pain.

All but one participant said they lived in the immediate Georgetown area. The one exception lived an hour and a half outside of town. She said she planned for her husband to drive her to Georgetown on his motorcycle, and indeed that is what they did.

5.2.1 Labor Signs

Women were asked what physical signs they used to determine that they were in labor and how they decided it was time to leave for the hospital. Of the 49 women we interviewed, 11 reported that they had been admitted to the labor and delivery unit directly from the ANC clinic or were hospitalized days before delivery. These women did not have to decide when to go to the hospital.

Among the signs of labor women reported watching for and responding to during their most recent pregnancy were: “pain,” “belly pain,” “belly gripping,” or “cramps” (uterine contractions); seeing “slime” or “white streaked with blood” (bloody show or sign of the mucus plug); or seeing their water bag (amniotic fluid sac surrounding the fetus) break. Two women said they experienced bleeding as a first sign of labor.

Most women (31) described “pain” or uterine contractions as the sign used to know they were in labor. Sometimes this sign was described in terms of its timing—how frequently the pain came—or in terms of its “hot” quality. At least six women used the adjective “hot” to describe whether the contractions were or were not very strong. One woman said:

The pain wasn't hot, and then the pain got hotter and hotter.

Another described the pain as

Hot, on and off.

Yet another woman said she didn't leave the house for eight hours after the pain started:

...because the pain wasn't that hot.

A few women also mentioned timing of contractions as an indication of when it was time to go to the hospital. However, those who discussed them were often not precise in their answers. One woman said:

I does wait till I getting the pain every minute or every five minute then is time to go. [16: HIV positive]

One woman was precise in timing her contractions, saying:

...felt my belly gripping like every three minutes. [36: HIV negative]

A few women reported having some trouble knowing whether the signs they were experiencing meant they should go to the hospital right away or later. One woman said that her contractions were uneven:

My pain was mixed up like 5 minutes, then 10 minutes. [17: HIV positive]

This suggests that her experience of pain did not occur exactly as expected.

Three women who had never delivered a baby before said that they looked for signs of passing “slime” or the mucus plug to confirm that they were in labor. One of these women said she was told at the ANC clinic:

If you see certain signs know that you're in labor. Like you ready to get this baby right, they say when you see slime please pack you bag and go to the hospital. [1: HIV positive]

When she did not see this sign she speculated about whether her other signs meant she should go to the hospital:

I was feeling pain, but not so much pain. [1: HIV positive]

Another woman also said that she did not experience the signs she thought she would have:

They tell we at clinic what signs we will get, but I didn't get none signs—cause they say you will get some sliming or some streaks of blood but I didn't have that. I just had the belly pains... [2: HIV positive]

A third woman said that once the pain began, she waited at home for a day and a half before going to the hospital. When asked why she finally went, she said:

I went to the hospital cause I did want to go. They say if you start getting slime and those type of thing you must come but I didn't passing no slime or anything... [22: HIV positive]

The release of slightly brown, pink, or blood-tinged mucus, “the bloody show” “mucus plug,” or loss of amniotic fluid from the sac surrounding the fetus (water bag) may or may not occur during the first or second stage of labor. If it does, it may not be obvious to a woman. Most women who tested HIV positive said they were advised not to wait for these signs, but rather to go in at any sign they saw first. Three women said they were advised by clinic nurses in the following way:

They said at the first pain don't wait as you water bag burst. For safety you go and get the treatment early. [27: HIV positive]

A fourth woman said that she was told:

When the pain is 10 minutes apart go to hospital. [17: HIV positive]

Contractions occurring 10 minutes apart would be considered early labor.

5.2.2 Transport Used and Person Who Accompanies Woman

All but one woman interviewed said they lived in the immediate Georgetown area, and travel to the hospital was no more than a 15-minute ride, usually less. One woman came from a farm, located one and a half hours out of town. Eleven of the women interviewed were admitted directly to the hospital from an ANC clinic or were admitted to the hospital days before they went into labor.

Of the women who went into labor outside of the clinic or hospital, the majority said they went to the hospital by taxi. A few women said they went by bus or minibus, one woman traveled by car, and one by motorcycle. Only one woman said that she could not get transport easily because of lack of a telephone and an infrequent bus schedule.

Only three women said that they traveled to the hospital unaccompanied. The rest were accompanied by the father of the baby, their mother, or another person (e.g., cousin, brother-in-law, daughter, godmother, neighbor).

5.3 Checking-in and Waiting to Deliver

The father of the baby or another family member, such as a mother, is not allowed to go into the laboring area or to assist the laboring mother. Only the labor and delivery nurses and other staff on duty provide assistance. In fact, most women said that no one waited with them to check in with the staff.

One participant described the nurse's instructions to her husband when she went to check in as follows:

*The nurse told my husband to put down the bag because he don't go in with me.
[36: HIV negative]*

The study proposal hypothesized that fear of accidental disclosure by hospital staff might lead some HIV-infected women to avoid hospital delivery. The data show, however, that family members are usually not with the woman or are with her very briefly when she checks in to the labor and delivery unit.

One woman who had told no one her HIV-positive status, was accompanied to the hospital by her husband. The interviewer asked her directly: "Were you afraid your status might be disclosed to your husband when you checked in at the hospital?" She responded:

I was nervous, yes, but they didn't...When the tablet was given no one was around. [14: HIV positive]

All the women interviewed indicated, directly or indirectly, that they knew they should bring their ANC card with them to the hospital when they went into labor. They knew because either they brought the card or they made other statements suggesting that they knew they should have brought it, but did not for some reason. Most women reported giving their ANC cards to the

nurse, either in the waiting area or in the delivery room. Three out of 48 women said they did not bring their ANC card to the hospital.

A large majority of women, both those who tested positive and those who tested negative for HIV, said they did not report their HIV status to the receiving nurse, but rather showed her the ANC card with the recorded results. They clearly expected the nurse to assess their HIV status and any other important information on the card and to know what to do.

None of the women interviewed said their HIV status was leaked to a family member during check-in; however, there were incidents of unwanted disclosure of HIV status on the inpatient wards. We describe these incidents later in the chapter.

5.3.1 Long Wait Time and Triage

When asked whether they had any problems with the hospital services, at least one-third of women spontaneously said that while in labor they had to wait in the waiting area a very long time before being examined by a nurse or taken to the labor room for delivery. Some women attributed their long wait to the lack of staff. One woman said:

They are understaffed the majority of the time you come, you got to sit down and wait hours. [40: HIV negative]

Other women suggested that the labor room could not accommodate enough women. One said:

Yes because I had to sit 2 hours on the bench because you know that labor room thing. [43: HIV negative]

When asked directly whether she stayed at home longer to avoid a wait on the bench, one woman said:

Yeah, I does wait home I don't like to go and sit down and wait, when I know that the baby almost coming then I does go. [16: HIV positive]

Some women said their waiting time was short because there were few or no other laboring women in the waiting area.

There were conflicting reports about whether HIV-infected women were attended to sooner. One woman described being triaged for delivery in a very busy waiting room, but not according to her HIV status:

I came before them [other patients] and the doctor asked me how many children I having and I tell him that this would make six children and he tell me that I have to wait because they having their first and the labor room was full too. [31: HIV positive]

Another woman who tested HIV positive suggested that because of her status recorded on her ANC card, she was helped sooner than others:

Well, I didn't wait long because I showed them the paper... the clinic card that had that I am HIV positive. [33: HIV positive]

5.4 Women Who Received Nevirapine

All the women who received a complete dose of nevirapine said they brought their clinic cards with them to the hospital, that they arrived more than an hour before delivery, and that their HIV test results were recorded on the cards. One woman described the process of getting nevirapine as follows:

The clinic card had a number they tell whenever I ready to get baby and I go into the labor room show the nurses the card. So when I go into the labor room that's the first thing I did, I show them the number on the card and the girl get up and get the things and give it to me. [42: HIV negative]

Many said that before administering nevirapine, the staff asked them whether they understood why they were getting a tablet.

...they came to me and said are you aware that you have to drink this [tablet] and I said yes and they gave me and I drank it. [27: HIV positive]

5.5 Women Who Did Not Receive Nevirapine

At least 11 (possibly 13) of the 34 women who tested HIV positive did not receive nevirapine before delivery—according to the records or their own reports—and one of their babies also appears not to have received nevirapine. The cases are analyzed below, according to the primary reason for non-receipt of nevirapine: five cases were primarily patient-related and six were primarily service-related. In the case of two women, we were unable to determine the cause of non-receipt from the data collected, but we present one case here.

5.5.1 Patient-related Reasons for Non-receipt of Nevirapine

Most women who tested HIV positive during ANC knew they should get to the hospital at the first sign of labor because they needed to take a “tablet” to prevent transmission of HIV to their babies.

According to what six women said in interviews and what was reported in the PMTCT hospital and ANC log books, there were two patient-related reasons why women did not receive nevirapine prior to delivery:

- The woman did not bring her ANC card to delivery (two cases)
- The woman did not arrive at the hospital in time to receive nevirapine (three cases)

A third patient-related reason for non-receipt of nevirapine was that the woman did not disclose her HIV-positive status to the nursing staff. This is not considered a primary reason for non-receipt of nevirapine because the primary responsibility for identifying HIV-positive women about to deliver belongs to the hospital staff reviewing ANC cards. However, women are also

responsible for ensuring the staff know they are HIV positive if they see that the staff are not aware of their status or are not performing their functions properly.

Even if the primary reason for non-receipt had been eliminated in some of these cases, a secondary factor would probably have led to non-receipt of nevirapine. Table 5 lists the number of cases according to primary and secondary patient-related reasons for the woman not receiving nevirapine prior to delivery.

<u>Table 5 Patient-related reasons for missing nevirapine dose</u>		
	Primary reason	Secondary reason
Did not bring ANC card	2	1
Did not arrive to hospital in time	3	
Did not disclose HIV-positive to staff		2

Did Not Bring ANC Card to Hospital

Case 1: One woman said she had been admitted to the hospital twice in the previous month, most recently the week before delivery. Since she brought her ANC card when she was hospitalized for pregnancy-related reasons, she said she assumed that her HIV results would be recorded on the hospital chart they had been using the previous week. Her pain started at 1 or 2 pm, and she arrived at the hospital around 3 pm. She said her baby was born vaginally at 4 pm. After the child was born, she said the staff person asked her for her ANC card. The hospital PMTCT log book recorded that the woman did not receive nevirapine because she was “admitted in second-stage labor.”

The hospital log book reported that the baby received nevirapine. The PMTCT ANC clinic log book said the mother did not receive nevirapine, but the baby did.

Case 2: Another woman reported not accepting post-test counseling after being told her HIV-positive results. She said she did not attend ANC clinic after that day and did not bring her card to the hospital. Since she did not receive post-test counseling, she did not know that she and her baby should receive a dose of nevirapine at delivery to prevent transmission of the virus. Nor did she tell the nurse she was HIV positive:

They didn't know I was positive because I didn't have my card. [16: HIV positive]

The hospital PMTCT log book had no record of her delivery. The PMTCT clinic log book recorded that the woman had not received nevirapine, but that the baby did.

Did Not Arrive to Hospital in Time

Three women who had tested HIV positive during ANC did not arrive at the hospital in time to receive an effective dose of nevirapine. Two reported that they delivered before reaching the hospital: one at home and one in a taxi. The third arrived in second-stage labor.

Case 1: This young woman said that her most recent pregnancy was her second HIV-positive pregnancy and that with the first HIV-positive pregnancy she did receive nevirapine. With this pregnancy, however, she said she did not receive nevirapine. She said that she had started ANC at five months, missed her six-month appointment, and that her baby was born at seven months. Her HIV test results were therefore not recorded on her card even though she knew her HIV status and knew she should get a tablet prior to delivery. On the day that labor started, she said:

I got pains early in the morning, didn't take it for nothing, just felt like normal pain right. And I stay and stay [at home] till I can't take no more.

She said her baby was born a half hour after arrival at the hospital. When asked whether she had received a nevirapine tablet prior to delivery, she said:

I had to ask them for the tablet because they forgot... Yes, I had the clinic card it's just that the results were not written on it.

According to the woman, the reason the results were not on the card was:

The day when I was supposed to come [to ANC clinic] to test I had already taken at the hospital so they had to use back the same results.

The general practice of verifying results in order to record them on a patient chart or other document is a means of double checking the result recorded on another legal document—the ANC card or patient chart, laboratory slip, or record kept at another clinic. This woman reported that her husband was sent back to the ANC clinic to have the ANC nurse record her test results on her ANC card and told to bring it back to the hospital staff, which he apparently did.

When asked whether or not she was afraid that her husband, who did not know she was HIV positive, would learn her results from the ANC nurse she said:

No, he didn't ask.

She said he is:

Ignorant bad.

The hospital PMTCT log book recorded that the woman did not receive nevirapine prior to delivery and noted that she was admitted in second-stage labor.

The baby was born half an hour after arrival in the hospital according to the mother, so she could have been past the point where nevirapine would have prevented transmission had she taken it. She said she thought the baby did receive nevirapine:

Yeah, I think they carry he upstairs for treatment. [6: HIV positive]

The PMTCT hospital log book recorded that her baby did receive nevirapine. The PMTCT log book recorded the mother did not receive nevirapine, but the baby did.

Case 2: The other woman who did not arrive for delivery reported that her baby was born in the taxi on the way to the hospital. Her pain, she said, started at 3 am.

I bathed in the morning and so on and I take the taxi. I leave home about 8:30 AM.

She said she went to the hospital alone because no one was around, and while she was in the taxi, she said:

Whilst we going around by the turn, my water bag start boring and so...and then she just came out screaming. [21: HIV positive]

She arrived at the hospital with her ANC card. She said the baby did receive syrup when she and the baby arrived at the hospital.

The PMTCT hospital log book reported that the mother had not received nevirapine and the baby had received it, but there were no notes to explain why the mother had not received nevirapine. The PMTCT clinic log book recorded the same results.

Case 3: One of these women delivered at seven months gestation. The labor, she said, took her by surprise:

I had the pain but I stayed home because I say I didn't really ready for the baby. I wait and wait until like this pain keep coming on, coming on. So it get too overbearing so I couldn't walk anymore so. I didn't really plan to get the baby home, born home there, normally I does go to the hospital...

She said that transportation was not immediately available, which complicated getting to the hospital:

We didn't really able to get to the hospital right away because we hadn't no taxi available because if you come out there we would've had to wait a long time for the bus... Then the bus with you know, the road at the back there is not so good, it like holey and them kind of thing. So I had to make the baby at home because I didn't had no, we couldn't get taxi and up there have no phone.

She said the baby's grandmother delivered the baby and:

She seemed to know what she was doing. [19: HIV positive]

This woman also reported that she was retested for HIV when she arrived at the hospital because her result was not recorded on her clinic card.

Both the hospital and ANC clinic PMTCT log books recorded that the mother did not receive nevirapine but the baby did.

5.5.2 Service-related Reasons for Not Receiving Nevirapine

According to what six women said in interviews and what was reported in the PMTCT log books at the hospital and ANC clinics, there were several service-related reasons for women not receiving nevirapine prior to delivery:

- No HIV test results recorded on ANC card
- Only the first HIV test result recorded on ANC card
- Hospital staff did not assess status from ANC card
- Hospital staff too busy to administer nevirapine in time
- Hospital staff did not record HIV test result taken in hospital on patient chart

Although the conclusion is based on the women's report of the circumstances and cannot be independently verified, details of the cases seem to suggest the women's reports were accurate.

These women had attended ANC clinic regularly and all said the nurse was given the ANC card with HIV-positive results recorded on it when they got to the labor and delivery reception area.

No HIV Test Results Recorded on ANC Card

Case 1: This woman started ANC at six months and attended the clinic once before delivering by Cesarean section at seven months because of pregnancy-related hypertension. Her HIV test results were not on her ANC card when she checked in to the hospital with symptoms of swelling of her feet and headaches. She said:

[I] went to the Georgetown hospital and they admit me and tell me my pressure was high, very high and they said they would keep me in and the night I went to bathe and I come back on the bed and I catch fits and I fell off the bed... That is when they rush me and tell me they got to take the baby.

She said she was tested at the hospital after the baby was born. When her condition was stable, she said, the doctor told her she was HIV positive. She added:

Then I didn't know what the word mean. Then they told me. [23: HIV positive]

There was no record of her delivery in the hospital PMTCT log book. The ANC PMTCT log book recorded that the mother did not receive nevirapine, but the baby did.

Only First HIV Test Result on ANC Card

One of the 13 women said she received conflicting HIV results on her two ANC HIV screening tests. The result of her first ANC HIV screening test was negative, but the result of the second one was positive. She said she received the results of the second test after her baby was delivered.

She said she had tested together with her husband at the ANC clinic during her fifth month of pregnancy and delivered vaginally at term. She reported receiving the results of her first HIV test during her seventh month of pregnancy, saying that at the time:

They give me my results, after it came back negative, the same day I had to go back and take a next one. [22: HIV positive]

At the time of her delivery, only the result of her first HIV test, HIV negative, was recorded on her card. But when her child was three days old she received a telephone call from the ANC nurse who said:

She wants to see me, very important. So then I say, I don't have to come back until six weeks. She says no, it's very important, so you must come. [22: HIV positive]

When she went to the clinic she was told her second HIV test result was positive. Her child received nevirapine at that time.

She speculated with the interviewer about her theory that the HIV results of the first test were not actually hers. She described how blood tube labels could have gotten mixed up in the blood drawing room as follows:

When I moved from the table he [lab technician] didn't put my name on it [blood tube] and somebody else went into the [blood drawing] room...normally they would take the tape off and put it on right away in front of you. But he didn't do that. [22: HIV positive]

She told the interviewer that she plans to get a third test to confirm whether or not she is HIV positive.

The hospital log book showed that her name was not recorded, but the ANC PMTCT log book recorded that both she and her child received nevirapine.

Hospital Staff Did Not Assess Status

Case 1: According to the woman's account, she arrived at the hospital just before 12 pm, gave the nurse her clinic card, and was given a bed in the antepartum area, where she spent seven hours until she delivered. Around the time she delivered she said the nurse had checked her cervix and told her she was 4 cm (out of 10 cm) dilated. At the same time, another nurse came by and told the attending nurse that she needed to put on a mask and gloves. Then she said:

It so happened that she [attending nurse] go to collect another girl because as soon as the girl come to the hospital her baby coming out.

When she saw the nurse again she said she told the nurse that her pain was worse:

It come on now and this pain isn't coming off and I say, nurse, this baby coming, this baby coming.

To which, she said, the nurse "hollered":

No, you're not ready, I just check you, you're only 4 cm.

At that point the woman said:

*[I gave] one push and she [baby] was out...I lay down on the bed and I wasn't saying nothing. I say well, I give birth to an HIV child, that is what I saying and I start think in on this thing and tears start coming from my eyes.
[32: HIV positive]*

The hospital PMTCT log book had no record of her delivery, and the ANC clinic log book recorded that neither she nor her baby had received nevirapine.

Case 2: Another woman said:

I walked with the clinic card...I give it to the nurse. The nurse didn't realize that I was HIV positive. She didn't really look at it and I was ashamed to tell them.

She was in labor at the hospital for three hours before delivering. The woman said that she had tested HIV positive for the first time at the ANC clinic and knew that she was supposed to get a tablet before delivery. Indeed, she provided many details of post-test counseling she received at the ANC clinic. She said the result was there, describing it as follows:

It mark at the side, the number was there to indicate that, it don't really mark HIV but just a code number.

She said she thought that her attending nurse either did not really look at her card or did not know what the mark on her ANC card meant. Another nurse, she said, did see her HIV-positive result:

*Afterwards a nurse recognize it [the code]. And that was long after the time was due for the tablet no more. You give the child two drops. That part was okay.
[10: HIV positive]*

She delivered mid-morning, she said, and the baby got the medicine late in the afternoon.

The hospital PMTCT log book recorded the mother's name and that she did not receive nevirapine, but her baby did. The hospital PMTCT log book also noted, "Didn't disclose; number not on card."

The PMTCT log book and her ANC clinic recorded that the mother did not receive nevirapine and that the baby did. Either the ANC clinic did not record the result on the clinic card, or the hospital staff reported incorrectly.

Hospital Staff too Busy to Administer Nevirapine in Time

Case 1: Another woman said she went to the hospital at 3 am and delivered around 6 am. When she arrived, she said:

There was plenty people there pregnant mothers sitting down on the bench waiting to go in the delivery room one by one.

She said she checked in with the staff.

...When I get a chance to go in, I talked to the nurse and give she the paper [clinic card].

She said that the nurse examined her and

Asked me questions and checked me and said I was 3 cm...

And the nurse, the woman said, told her she would bring the tablet of nevirapine:

I show she the thing [clinic card] and she say she gon bring it.

Meanwhile, she said:

The pain come on more hot and me ent see she bring nothing and I get call and after I see was near time I show a nurse [different nurse]...it was too late cause she din already come out.

The second nurse, she said, started to “row” with the first:

And [the attending nurse asks] if she know what this sign is for what.

When asked whose fault it was that she had not received the tablet she said:

The nurse [fault] because I show her the sign and I tell she and she tell me hold on and she never gave me [tablet]... When the nurse approach she say ent know is wha is wha. [26: HIV positive]

The hospital PMTCT log book recorded that the woman did not receive a dose of nevirapine and noted, “Card not presented upon admission.”

The hospital PMTCT record said the baby did receive nevirapine. The ANC PMTCT log book recorded the woman did not receive nevirapine, but her baby did.

Inpatient Staff Did Not Chart HIV Test Results on Patient Chart

Case 1: Another woman who attended both a community ANC clinic and the Georgetown Public Hospital Corporation ANC clinic, after being transferred there for a high risk pregnancy, said she did bring her clinic card but it was the Georgetown Hospital ANC card. Since she had been tested for HIV at the community ANC clinic, the HIV test results were written on that ANC card and not on the Georgetown ANC card. This woman had been HIV positive for several years and she said she told the nurse she was HIV positive and was actually retested as an inpatient before she delivered. She said she told the staff:

I said I am an HIV positive and I show them the card, because they asked me for the card. But I did not walk with that card; I walked with the clinic card that I got from the hospital at the maternity clinic and they said that they did not see no HIV on the card and they did another HIV test. [4: HIV positive]

She was admitted as an inpatient for two days before delivering her baby.

This woman told us that she did get nevirapine prior to delivery; however, the PMTCT hospital log book stated she did not receive nevirapine, and noted, “No number on chart; oversight.” The hospital log book recorded that the baby did receive nevirapine. The PMTCT ANC log book reported the woman did not receive nevirapine, but the baby did.

5.5.3 Inconclusive Case

One woman reported she was admitted to the hospital in the morning, tried to deliver vaginally, but had a Cesarean section in the evening.

When asked whether she had received her HIV-positive results prior to delivery, her answers were contradictory. In one interview, she said she told a friend about her results when she was still pregnant; in another, she said she thought she received her HIV results after delivery. She reported that she did not know she needed a tablet at delivery:

No, they didn't tell me that [I needed to get a tablet].

It was clear from her statements about her HIV status that she was in denial about being infected with the virus and this undoubtedly affected how she was able to observe and report her experiences. She did say that after her Cesarean section, the baby received some kind of treatment:

The baby got treatment because when I was done delivery [Caesarean section] ...the doctor asked me if I had any problem and I tell him because he said he see the [test result] number. Because it [HIV results] goes by a number, so he see the number and he explain to me but still I can't remember. [34: HIV positive]

The hospital PMTCT log book recorded that both the mother and baby received nevirapine. The ANC PMTCT clinic record from which she was recruited recorded that neither the mother nor her baby received it.

5.6 Baby Did Not Receive Nevirapine

Many women could not say whether or not their babies received nevirapine because their baby was taken to the nursery after delivery for varying periods of time, depending on how healthy they were when born. It was difficult to get firm information on this from the women themselves. The data showed that only one baby definitely did not receive nevirapine within 72 hours of delivery, and one more possibly did not.

One baby may have received a dose of nevirapine, based on what the woman said, but it is not recorded in the hospital PMTCT log book.

Case 1:

A woman who actively worked against intervention by not attending an ANC clinic for post-test counseling, by not bringing her clinic card, and by not telling anyone her HIV status before or after delivery, said that her baby had not received nevirapine.

Case 2:

In another case, a woman said her baby got nevirapine but the record showed that neither the mother nor the baby received a dose. She reported to us that she did not receive the tablet because the nurse was busy. When the nurse came back after delivery she said the nurse told her she had to give the baby something in her mouth. She said the nurse had added, before giving the medicine:

You know the situation right? And I said yes. [32: HIV positive]

Her name did not appear in the hospital PMTCT log book and the ANC log book said both had the mother and the baby did not receive nevirapine.

Case 3: Near Miss

One of the women said she had not received her HIV results and thus had no post-test counseling. She did not know that she and the baby should get nevirapine at delivery. She started ANC at seven months and delivered outside of the hospital at nine months. She said she went to the hospital immediately after the baby was born, with her ANC card:

But the clinic card had everything else but I had to repeat the [HIV] test because they wasn't too sure about that's why I didn't get the results of the HIV test right away.

Although the result was not on the card, a nurse who worked at her ANC clinic happened to be in the labor and delivery area when she came in with the just-delivered baby.

Right away when she see me and the baby come [to the hospital] she took the baby, carry it upstairs and give the baby the syrup or what so ever. [19: HIV positive]

Both the ANC clinic and PMTCT hospital log books recorded that the baby did receive a dose of nevirapine.

5.7 Record Review

For purposes of this study, we reviewed two kinds of PMTCT log books: one kept on the labor and delivery unit at the hospital and one kept at each of the ANC clinics. Below, we compare log book records.

Of the 34 participants testing HIV positive during ANC, the names of nine were not found in the hospital PMTCT log book: six of the missing names were those of women who, according to our data, did not receive nevirapine.

Further, in one case, the records conflicted about whether the mother and/or baby received nevirapine at delivery: the hospital PMTCT log book said they both received nevirapine and the ANC clinic PMTCT log book said both mother and baby did not receive it.

In two cases, the woman's report of receipt of nevirapine conflicted with what was written in the log book: in one case the woman thought she received nevirapine but did not according to the hospital PMTCT log book. In the second case, the woman said she saw the baby receive nevirapine but the PMTCT log book did not indicate this.

The study did not collect data on the process used by staff to record lab results onto the ANC cards or into these log books. Thus, the cases will be presented to staff to determine the causes and remedies to the conflicts in log book records.

5.8 Reflections on Hospital Delivery Service

All 48 women who were asked to recount their recent delivery experience at Georgetown Hospital were specifically asked what they did and did not like about the experience, and how they felt the services could be improved. The comments of women who tested HIV positive and HIV negative were very similar and are analyzed together in this section. As discussed earlier in this chapter, and by the previous woman quoted, the most common response to the question, "How could delivery services be improved?" was by making the long wait in the labor waiting area shorter (see analysis above). Other answers to what women did and did not like are described below.

5.8.1 Bedside Care

The majority of women expressed appreciation in one way or another for the care provided by the nurses. One woman said that although she had a long wait to get into the labor room, the nurses were nice:

*[They] rubbed my back for me. They fan me; they spoke to me and everything.
[48: HIV negative]*

The 34 participants who were HIV-infected were asked this follow-up question during the discussion about their hospital care: "Did anyone treat you differently because you were HIV positive?" The majority of women (22) responded "no times." One woman elaborated on her response:

They treat me like a human being...no one didn't scorn me or anything... I felt comfortable. [1: HIV positive]

The caring attention from nurses described by HIV-infected women was very similar to that described by the HIV-negative women. One woman said that when she told her nurse she was in pain, the nurse:

Come hold my hand or rub my belly and they come and rub my belly. They didn't shun me. [18: HIV positive]

Another said she felt at home with the nurses at the hospital:

They treat me like if they are my mothers, like if I am their child right, they didn't treat me bad or look at me funny you know. [15: HIV positive]

Women's descriptions of what they did not like were similar to what they said about ANC services: some staff were not empathetic to their pain. Most women who commented on their care were careful to give mixed reviews, describing some nurses as kind and others as unsympathetic. One woman said:

Some of them are not nice...you getting pain you saying nurse come help me right, they would say I didn't tell you to go and get that and they start hollering on you. But some of them they would come, they would rub your back, they will say lie down on your side and breathe in and breathe out. [2: HIV positive]

Another woman, who was admitted to the hospital several days before delivery, also mentioned that although most nurses were satisfactory, she had had some problems with the night staff:

Most of them was okay...some of them working night shift, oh gosh...if you get pain they tell you lie down and wait sometimes they would shout at you they don't be nice... I started getting pain like about 11 pm and I frighten to go and tell them...when I couldn't bare it anymore then I go and tell them. [42: HIV negative]

One woman, however, seemed to have had a negative experience, which clouded the whole experience. She said:

The pain wasn't much but the nurses at the Georgetown hospital put me through hell... Since I walked into the labor room obviously I was in pain and I just gave a sound like clinking my finger about the pain and she stared hollering on me. Shut up you don't know you'll feel pain. You come here to feel pain, what you expect and that short of thing... You mustn't cry out. [29: HIV negative]

5.8.2 Hospital Routines and Conditions

Some women's comments about what they did not like about services concerned the hospital routine. One woman said she was awakened at 4 am to take a bath:

I was feeling weak but they hurry you up and the bathroom is far...

Once she arrived in the bathroom, she said, there was no water. Several other women complained that the bathrooms in the hospital were not clean enough.

In addition, many of the women interviewed said that they and their baby had shared a single bed with another woman and baby who had just been delivered, one lying with her feet at the top of the bed and the other with her feet at the bottom of the bed. Although women seemed to understand about the bed shortage and the predicament of the nursing staff, they said this nevertheless made it difficult to get good sleep. One woman said:

Yes it is uncomfortable because you can't get to sleep properly at nights. [12: HIV positive]

In addition, one woman described the problems encountered if you have habits different from your bed mate's. She described the situation as follows:

There was a girl and then a baby and the girl didn't look proper for me to be next to her. She had on her own clothes and she had a razor blade scrapping her nails. I nearly beat her because she was scrapping off nail polish and my baby was there... I told her to take the bed and I would sit and sleep. [37: HIV negative]

5.9 Reports of Discrimination Because of HIV Status

A minority of women (7/34) reported having negative experiences they said were related to being HIV positive. These reports are grouped according to the following types of incidents: taking the moral high ground, fear of infection, discrimination based on appearance, and cases of unwanted disclosure of HIV status.

5.9.1 Taking the Moral High Ground

One woman said the following incident occurred when she was checking in for delivery at the change of nursing shifts:

Some of them started talking and laughing and carrying on at a rate in the labor room while me and five other girls are in pain.

In response, she said she told a doctor trainee passing by that the nurses were not doing their job. For this, she said she was left to wait longer than others and added that one of the nurses asserted her authority by holding up her ANC card and saying:

"You see this," and she pointed to the number on top of the card, she said, "when ya'll got these things you must not behave like that." [33: HIV positive]

Another woman who had been HIV positive for several years described a moral insult she received from a nurse at the hospital:

The nurse holler, how I know I got HIV and why I go and sex with the man. [29: HIV positive]

5.9.2 Fear of Infection

One woman complained that the nurses were not comfortable preparing her for surgery. She said she said she told the nurses:

All you have to do is to take your necessary precautions and put on your gloves and so forth. [27: HIV positive]

At this point, she said:

Two nurses came up and took over and to me they were much more relaxed. [27: HIV positive]

5.9.3 Discrimination Based on Appearance

Several women suggested that if you do not look different from other women you receive similar treatment. For example, when asked if she was treated differently because of her HIV-positive status, she responded:

I know I don't treat differently, I does treat the same.

She added that this was because she looked normal.

...because a lot of my friends tell me I don't look so...I don't look like an HIV person. [21: HIV positive]

Another woman, however, was not as lucky. At the time of delivery she said she was experiencing health problems, manifesting as spots on her skin. She said that because she looked different from others she did not receive good treatment at the hospital. She described two incidents as evidence. The first occurred when she was admitted pre-delivery. At that time she said that one of the nurses called out:

You have to put on a gloves before she scratch you or scrape you or anything.

After delivery, when her baby was in the nursery, she said that although some nurses were very kind, letting her participate in mixing tea for her child, others would not let her participate but rather would tell her:

Hey don't touch them thing. Wait out there I gon give you. [4: HIV positive]

5.9.4 Unwanted Disclosure of HIV-positive Status

Two women described incidents where their HIV-positive status was told to others without permission when they were admitted to the inpatient postpartum ward.

One said the incident occurred when she was read her HIV test result in the ward.

She [nurse] read the results to me, she read it to me in bed and they had another girl in there near to me and she could hear what she telling me...she turn and she watch me...all she do is shake she head. [6: HIV positive]

Another woman said she knew that the nurses and the staff gossiped about her because she had a friend working on the ward who told her:

They scandal my name in the whole ward... Everybody in the ward went know I have AIDS...and let me tell you it was really sad. [14: HIV positive]

5.10 Chapter Summary

The women interviewed for this study were asked a range of questions about their birth planning, birth stories (including labor signs and getting to the hospital), and hospitalization experiences during their most recent pregnancy. A summary of their reported experiences follows.

Most women who tested HIV positive (31) used any early labor sign to know when to go to the hospital for delivery, and said ANC staff encouraged them to go to the hospital at the first sign of labor. The exceptions were three HIV-positive women, pregnant for the first time, who reported waiting through progressive labor contractions to see signs of the mucus plug that never came.

Most women lived in the immediate Georgetown area and went to the hospital by taxi (no more than 15 minutes away), accompanied by someone. Three women said they went unaccompanied. One woman in labor was taken to the hospital by her husband, traveling 1.5 hours by motorcycle.

Many women said they experienced long waits on the wooden benches in the labor and delivery check-in area before being admitted to the labor room due to staff shortages and lack of labor beds during high-flow periods. A few women said they stayed home until near the time for delivery, to avoid the wait.

The large majority of HIV-infected women knew that they should receive nevirapine or a “tablet” during early labor. Most women who received nevirapine said they did not tell the delivery unit receiving nurse their HIV status, but rather showed her the ANC card with the results.

Eleven of the 34 HIV-infected women interviewed did not receive nevirapine at delivery: five for patient-related reasons and six for service-related reasons.

Patient-related Reasons for Not Receiving Nevirapine

- Did not arrive to hospital during the first stage of labor (three cases):

One woman had difficulty getting transportation in her neighborhood and had no telephone available, another delivered in the taxi on the way to the hospital, and another arrived in the second stage of labor.

- Did not bring ANC card to hospital (two cases):

One woman had just been discharged from the hospital for pregnancy-related problems and thought the staff had recorded her status on her hospital chart, since they knew of it. Another dropped out of ANC when she was told of her HIV-positive status, and she did not bring her card to the hospital.

Service-related Reasons for Not Receiving Nevirapine

- No HIV test results recorded on ANC card (one case):

This woman first attended ANC at six months and delivered by Cesarean section at seven months; thus she had made only one ANC visit and never received her HIV test results.

- Only the first HIV test result was recorded on the ANC card (one case):

The first HIV test was negative (possibly because of a laboratory error) and the second was positive. She did not learn the second result until three days after delivery.

- Hospital staff did not know status (two cases):

The attending hospital delivery staff appeared not to assess or understand the meaning of the HIV-positive test result code recorded on the ANC card.

- Staff too busy to administer nevirapine in time (one case):

A woman reported not receiving nevirapine because the staff were too busy with other patients in the labor room to bring her medicine before she delivered.

- Inpatient staff did not chart HIV test on patient chart (one case):

A woman was an inpatient when she went into labor and had a repeat HIV test in the hospital after telling the nurses she was HIV positive. The PMTCT log book said “no number on chart: staff oversight.”

The babies of all but one of the 34 HIV-infected women received a dose of nevirapine syrup within 72 hours. The mother of the baby who did not receive a dose of nevirapine did not receive a dose herself; she had dropped out of ANC service after hearing her positive results, but before post-test counseling was completed. She was not aware that she and her baby needed nevirapine to prevent HIV transmission.

The hospital PMTCT log book did not list the names of nine of the 34 HIV-infected women who participated in this study, although they did deliver their babies at the Georgetown hospital.

No cases of unwanted HIV test disclosure were reported during check-in to the labor and delivery unit; however, two women said they experienced unwanted disclosure of their HIV-related test results following delivery in the inpatient delivery ward.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

Eighty-nine women were interviewed on a broad range of topics related to their general use of ANC and hospital delivery services, as well as to HIV testing and disclosure experiences, birth stories, and hospital delivery experiences for their most recent pregnancy. Examining this broad range of women's experience revealed many of the reasons why women did or did not complete all recommended steps to prevent vertical transmission of HIV. We discuss these reasons below in relation to each intervention. Women's experiences of unwanted disclosure of HIV test results and HIV-related shame and discrimination are also discussed.

6.1 HIV Counseling and Testing

The first step in PMTCT is to test all pregnant women for the virus. The program in Guyana calls for testing women at the first ANC visit. If she tests HIV negative, another test is performed toward the end of pregnancy. ANC staff also promote partner testing. The facilities use laboratory-based testing and require the woman to make at least two ANC visits to complete the testing process. Most women begin attending ANC in their first or second trimester of pregnancy, and given the schedule of visits, they generally attend the clinic often enough to receive HIV counseling and testing at least once; many receive it twice. A small but noteworthy number of women (3/34) who tested HIV positive, however, did not have even one HIV test result showing on their ANC cards at the time of delivery, even though they had been tested. In two cases, this was because the woman had not attended ANC more than once before having an early delivery, and in another case because the results of her second HIV test (positive) were not told to the woman or recorded on her ANC card until after delivery. At least five women who said they were tested twice reported not having received the result of their second HIV test prior to delivery.

Most women attending the ANC clinic were aware that the HIV test is offered, and some had taken HIV tests before: 12 had previously tested HIV positive. They generally saw the test as a part of the ANC diagnostic screening process in which they have historically participated. A large majority of women accepted an HIV test and said they felt it was their choice. Although most women said they were individually counseled prior to an HIV test, not all said they received individual counseling. And, although the majority of women feel the HIV test is voluntary within a system where testing is reinforced more than once, at ANC and the hospital not everyone felt it was voluntary. A few women reported they were coerced into testing or that the test was done without their knowledge.

Rather than being tested for HIV themselves, a significant number of male partners of participants took the result of the woman's ANC HIV test, either positive or negative, as a reflection of their own HIV status.

6.2 Receipt of Nevirapine Prophylaxis by Mother during First Stage Labor

The second step in preventing vertical transmission of HIV is for all women who are HIV infected to receive a single oral dose of nevirapine during the first stage of labor. This preventive

step is, by policy, administered only through the hospital labor and delivery unit staff. If an HIV-infected woman does not get to the hospital in the first stage of labor, she will not receive nevirapine. The study hypothesized that non-disclosure of HIV-positive status might have led some women to avoid hospital delivery, but this was not the case. All the women who participated in the study at least attempted to have a hospital delivery. In addition, a large majority of women who tested HIV positive knew they should receive a tablet during labor at the hospital to prevent HIV transmission to their babies. Eleven of the 34 women interviewed who tested HIV positive, however, did not receive nevirapine at delivery: five for patient-related reasons and six for service-related reasons.

The patient-related reasons included not arriving to the hospital during first-stage labor (3) and not bringing their ANC cards to the hospital for delivery (2). Reasons for not arriving to the hospital in first-stage labor included: one woman said she lacked a telephone and ready transport in her neighborhood, and two women said they simply waited too long at home. The data also suggested two other possible reasons why some women might delay getting to the hospital: three women delivering for the first time said they delayed because they were waiting for a set of labor signs rather than leaving after the first one appeared, and some experienced women said they stayed at home to go through labor where it was more comfortable.

The service-related reasons why six women interviewed did not receive nevirapine at delivery included the following: no HIV test result recorded on ANC card (1); only the first HIV test result recorded on card (1); hospital staff did not assess ANC card and/or HIV test codes properly (2); staff too busy to administer nevirapine in time (1); and inpatient staff did not chart HIV test on patient chart (1).

Although the traditional challenges to providing high-quality delivery services, such as inadequate staffing or patients arriving in the late stages of labor or after delivery, lead to non-receipt of nevirapine, the biggest obstacle to provision of ARV prophylaxis was the ANC card system. The problems with using this system to communicate to delivery staff the HIV status determined during ANC care included:

- Incomplete results recorded on the card. This could occur if a woman delivers early, does not attend ANC often enough, started ANC during the sixth month or later, or for another reason.
- The woman not bringing her ANC card to delivery. This could easily occur for legitimate and predictable reasons such as: she is not at home when labor begins; the card is lost; she forgets because she is feeling bad; she brings the wrong card from the high-risk clinic; she is admitted to hospital prior to delivery; or she assumes she does not need the card because she was just admitted to the hospital the week before.
- The staff does not assess the ANC card properly or does not understand the anonymous HIV result code system. This could occur because of lack of training, rotation of hospital staff, use of unqualified staff to fill in staffing gaps, or because the patient-to-provider ratio is so high that the staff cannot fulfill all their responsibilities.

In addition, the PMTCT record system does not seem to capture all HIV-positive women who deliver, including some who received a complete dose of nevirapine.

6.3 Receipt of Nevirapine by Baby within 72 Hours of Birth

The babies of almost all of the women who did not receive nevirapine before delivery received a dose within 72 hours of birth. This intervention is more easily provided because the medicine will be effective if given anytime within 72 hours after birth. During the 72-hour window of opportunity, a nurse who may have had little time to devote to a patient during delivery may review the ANC card or patient chart or consult with another nurse and discover that the woman who just delivered was HIV positive. A rapid HIV test of the mother could easily be administered in this period as well. With all this, there would still be time to give the nevirapine syrup to the baby even though the opportunity for the mother has passed. In addition, if a woman delivered by accident outside of the hospital, she would have plenty of time to get her baby to the hospital for examination after delivery and to make sure the baby received nevirapine then. An ANC nurse may learn of a delivery of one of her patients whose second HIV test came back positive. She likewise has several days to communicate with the woman about her status and the need for nevirapine for the baby. For all of these reasons, nevirapine was given to all but one of the babies of the women who themselves did not receive nevirapine.

6.4 HIV-related Stigma

People living with HIV/AIDS in Guyana, as elsewhere, are socially stigmatized because of their health condition. The shame related to being HIV positive contributed to at least two women not receiving nevirapine: both said they were ashamed to tell the nurse they were HIV positive prior to delivery, even though they could see that the nurse did not know. Two other women, however, did tell the nurse their HIV status at delivery.

The assumption that opportunistic infections experienced by HIV-infected people (especially the skin conditions) are contagious to those not infected with HIV leads to HIV-infected people who appear sick being excluded from normal social contact and sympathetic treatment at the hospital. Of course, people with normal immune systems are not susceptible to most opportunistic infections of HIV-infected persons, whose immune systems are compromised. The exception is tuberculosis. Conversely, in the absence of signs of illness, an HIV-infected person will have a ready alibi and the social support to deny HIV infection.

Although no unwanted disclosure of HIV status occurred among participants when they were checking in for labor and delivery, a few women testing HIV positive provided examples of unwanted disclosure of their HIV test or related results during their inpatient stay. This usually occurred when test results were given to women at their bedside in a ward with other patients within earshot.

6.5 Recommendations

The following recommendations are based on the findings of this study.

- Update the national PMTCT protocols to ensure that all women who come for ANC, regardless of the length of their pregnancy, are tested for HIV and receive their results:

- Use rapid testing where possible to increase access to HIV testing. In places adopting rapid testing, a quality control algorithm could be added to reanalyze a percentage of negative tests with enzyme-linked immunosorbent assay (ELISA) tests.
- Add PMTCT program components to ANC and delivery care services:
 - Increase information, education, and communication (IEC) and counseling efforts to encourage pregnant women to receive ANC starting with the first trimester. Promote the idea that HIV testing is a standard part of ANC and is important to ensure an optimal pregnancy outcome for the mother and child. Women who deliver at home should be counseled to receive HIV testing when they first bring their infant in for vaccinations or other care. Health care providers should use ANC visits, as well as deliveries, as opportunities to educate women about HIV transmission and prevention.
 - During counseling sessions, emphasize the concept of discordant couples.
 - Provide added privacy in the labor and delivery units for the administration of nevirapine.
- Improve PMTCT record keeping for ANC and delivery:
 - Strengthen communication between HIV testing services and the ANC and delivery units. Use color coding or some other unobtrusive system to ensure that positive laboratory results are linked to patients' hospital records and ANC cards.
 - Keep up-to-date registers of HIV-positive results among pregnant women in the ANC and delivery units, for quick checking during ANC consultations, labor, and delivery.
 - Include registry of the administration of nevirapine on delivery records (e.g., partograms, hospital records) and ensure linkage with PMTCT records.
- Enhance training for health care providers on HIV testing:
 - Provide in-service and pre-service training for health care providers emphasizing the importance of checking whether pregnant and postpartum clients have been tested for HIV, and offering HIV testing to all clients who have not been tested.
 - Provide special training to PMTCT providers on counseling skills, protecting clients' privacy and confidentiality, and maintaining a positive attitude with clients. These skills should be included in on-the-job guidelines for optimal provider performance.
- Reduce HIV-related stigma:

- Behavior change campaigns should emphasize not only that HIV cannot be transmitted through casual contact—such as sharing food with people who are HIV positive—but that because of recent advances in the treatment of AIDS, people who are HIV positive can now live a long time and have a good quality of life. Such messages will encourage women to take advantage of PMTCT services.
- Community outreach:
 - Consider setting up a system involving community outreach or health workers to follow up on pregnant women who test positive but do not keep their scheduled ANC visits, or do not deliver at the expected health institution.
 - Help HIV-infected women develop a transportation plan to assist them in keeping their follow-up ANC visits and in bringing their infants to receive nevirapine within 72 hours postpartum.

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APPENDIX 1

Topic Guide Phase I: HIV Counseling and Testing

Background Information

- Age?
- How many children, roughly what ages?
- Age at youngest or current pregnancy (pregnancy of greatest interest for this study)?
- What is your marital status?
- Family of origin—home town, siblings, schooling. Did you attend school? How many grades? Where? Did your siblings attend?
- What is your ethnicity?

Use of ANC Services

- What month did you begin coming to ANC? Which clinic?
- How many times did you attend for last pregnancy?—Q-month/Q-two weeks/Q-one week last month.
- Did you attend for other children?
- Do you find ANC helpful? How so?
- What did you do to try to make sure you had a healthy child (e.g., eat, rest, take medicine, exercise, tests, clinic, etc.)?
- Do you usually take all the screening tests recommended by the nurses? Why? Why not? Which ones did you have with this pregnancy?

HIV Testing Experience at ANC Clinic

- Did you know before you came to the clinic that you might be asked to get an HIV test? How did you know this?
- In what month of pregnancy were you offered the test?
- In what month of your pregnancy did you get the test?
- In what month of your pregnancy did you get the results?
- Did you discuss the offer of an HIV test with anyone after a clinic visit? Probe experience (partner, nurse, friend). What did they say that convinced you or dissuaded you from the test?
- If they have not been tested for HIV yet: Do you plan to be tested in the future? Under what circumstances would you accept an HIV test?

Was the Test Voluntary?

- Did you feel free to decline or accept the HIV test? Why or why not? Probe reasons.
- Why did you accept HIV testing? What most influenced your choice to be tested? Why did you decline testing? Probe reasons.
- Did you go back to the clinic for results? Why or why not?
- Did you discuss the results with your partner?

General Knowledge of HIV and AIDS and Prevention

- What is the difference between HIV and AIDS?
- What is the cause of HIV and AIDS (proximal and ultimate)? How does it get spread around?
- Does having HIV when you are pregnant affect the baby?
- What can a pregnant women with HIV do to protect her baby from getting HIV?
- How is HIV or AIDS prevented?
- Probe the condom issue.
- HIV and AIDS are causing suffering; what can be done?
- When was your first HIV test?

If not at ANC: *Inquire how many times they tested, and when and where for each.*

General Views of Routine HIV Testing of Pregnant Women and Stigma

- Do you think that pregnant women should be routinely tested for HIV? Why, or why not?
- How does HIV affect pregnant women?
- Is there a stigma attached to persons living with AIDS?
- Do you know other people with HIV?
- Do you feel this stigma is different for pregnant women?
- Who is to blame for HIV/AIDS?

Helpful? How to Improve Services?

- What parts of your ANC visit made you feel comfortable about telling people about your HIV testing experience and results?
- How could providers at the clinic be more helpful to you?

APPENDIX 2

Topic Guide Phase II: HIV Counseling and Testing, ARV Prophylaxis, and Labor and Delivery Experience

Background Information

- Age?
- How many children, roughly what ages?
- Age of youngest pregnancy (pregnancy of most interest for this study)?
- What is your marital status?
- Family of origin—home town, siblings, schooling. Did you attend school? How many grades? Where? Did your siblings attend?
- What is your ethnicity?
- Where do you live now? (Estimate the time it takes to travel to clinic from home, and find out if rural or urban).
- Who lives with you now?
- Are you working? Where and how much?

(If the child isn't here) Who is watching the baby?

Use of ANC Services

- What month did you begin coming to ANC? Which clinic?
- How many times did you attend for last pregnancy?—Q-month/Q-two weeks/Q-one week last month.
- Did you attend for other children?
- Do you find ANC helpful? How so?
- What did you do to try to make sure you had a healthy child (e.g., eat, rest, take medicine, exercise, tests, clinic, etc.)?
- Do you usually take all the screening tests recommended by the nurses? Why? Why not? Which ones did you have with this pregnancy?

Most Recent Pregnancy

HIV Testing

First HIV test—If not at ANC, inquire how many times they tested, and when and where for each.

HIV Testing Experience at ANC Clinic

- Did you know before you came to the clinic that you might be asked to get an HIV test? How did you know this?
- In what month of pregnancy were you offered the test?
- In what month of your pregnancy did you get the test?
- In what month of your pregnancy did you get the results?

- Probe reasons for gaps between getting, taking, and receiving test results.
- Did you discuss the offer of an HIV test with anyone after a clinic visit? Probe experience (partner, nurse, friend). What did they say that convinced you or dissuaded you from the test?
- Why did you accept HIV testing? What most influenced your choice to be tested?
- If they have not been tested for HIV yet: Do you plan to be tested in the future? Under what circumstances would you accept an HIV test?

Was the Test Voluntary?

- Did you feel free to decline or accept the HIV test? Why or why not? Probe reasons.
- Did you get your results?
- Why did you decline testing? Probe reasons.
- Did you go back to the clinic for results? Why or why not?
- Did you discuss the results with your partner?

General Knowledge of HIV and AIDS and Prevention

- What is the difference between HIV and AIDS?
- What is the cause of HIV and AIDS (proximal and ultimate)?
- How does HIV affect pregnant women?
- What can be done for HIV-infected pregnant women and their babies?
- How is HIV prevented?
- How is AIDS prevented?

How many times have you been tested for HIV? (HIV testing history, chronological, where, when, why, result)

Relationship History (Sexual Partners)

Begin with father of the youngest child or current pregnancy and work backwards:

- How long with baby's father?
- Living together or just visiting?
- If not together, reason for separation?
- Were you trying to get pregnant?
- If person didn't want child: Did you want to abort? History of those events?
- Is the father providing support?

Prior sexual relationships? Together how long, and how many kids together?

- How long with each partner?
- Living together or just visiting?
- Reason for separation?

Support System and History of Disclosure

- Who are the people you are closest to?
- To whom have you told your status?
- Would anyone be uncomfortable with your testing for HIV or knowing your HIV status? What are your concerns about telling X that you were tested for HIV?
- Have you disclosed that you were tested for HIV or your status (positive or negative) to anyone? How did you tell X that you were tested? What happened next? Helpfulness of providers?
- What aspects of provider consultations helped you disclose testing and results to significant others? How and why?
- How could ANC providers be more helpful to you?

Birth Plan and Birth Story

- Did you have a birth plan? What was it? Who was going to help you?
- How did the plan work out? Was this discussed with the ANC nurse? What did she advise you? (Or, was it a difficult delivery? Tell me the story, for example, labor, water breaking, getting to hospital.)
- At which hospital did you deliver?
- What was the first sign that you were going into labor? What happened next?
- How long was it before you decided to go to the hospital?
- How did you get there? What vehicle, how long, how comfortable?
- Did anyone accompany you to the hospital? If so, who? Did they know your HIV status? Were you afraid they might find out from the hospital staff?

Hospital Experience and Initiating Infant Feeding

- When you arrived at the hospital, what happened? How many centimeters was your cervix dilated when you were first checked at the hospital?
- Did you receive ARV prophylaxis at the hospital during labor? How long before delivery did you get it? In what form was the medication? Did you notice any effects from it?
- Did your baby receive the ARV medicine? How long after birth did the child get the syrup? Did the child have any effects from the medicine?
- How long were you in the hospital postpartum?
- Which unit/ward did you stay in? (The HIV ward or the postpartum ward?)
- What happened during your postpartum experience?
- Did you have any experience of stigma or prejudice in the delivery or postpartum ward?
- Did you breastfeed following delivery?
- If not, did anyone comment on the fact that you were not breastfeeding when you were on the ward? What did they say? What did you say?
- Do you plan to have the child tested for HIV? When? Is the child getting some kind of treatment or protection from HIV/AIDS now?

Infant Feeding and Postnatal Clinic

- How are you feeding your child?
- Are you experiencing any problems with feeding your baby?
- Did you ask the nurse for help with this? Did the nurse help you solve problems related to infant feeding?
- How often are you attending the postpartum clinic?
- Did anybody ask you why you weren't breastfeeding while waiting for your appointment? What did they say? What did you say? What happened? (baby bottle of water only strategy? Other strategy?)
- Is the baby being treated in any way (medicine) because of your HIV status?
- Do you plan to have the baby tested?
- Helpfulness of providers?
- What aspects of provider consultations helped you disclose testing and results to significant others? How and why?
- How could delivery, postpartum, and postnatal providers be more helpful to you?

Knowledge of HIV and AIDS

- What are the symptoms of HIV?
- What are the symptoms of AIDS?
- (If positive) Are you sick with symptoms? How so?
- What other experiences have made you feel stigmatized or feel as if you were experiencing prejudice? Probe for three different experiences.
- Who is to blame for HIV and AIDS?

History of HIV/AIDS Treatment

- Have you ever been treated for HIV or AIDS?
- When were you first treated? When did you first present symptoms, receive medicine, what kind, how many times a day?
- Which clinic treated you?
- Did you experience any problems with the clinic providing treatment?
- How does the medicine make you feel? (side effects)
- How has the diagnosis of HIV changed your life?