BARRIERS TO HUMAN IMMUNODEFICIENCY VIRUS (HIV) TREATMENT PARTICIPATION DURING THE PERINATAL AND POSTPARTUM PERIODS: A COMPARISON OF MATERNAL AND INFANT HEALTH OUTCOMES

By

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This document is dedicated to strong, healthy mothers, children, and families.
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Public health efforts have yielded a dramatic decrease in the number of infants born Human Immunodeficiency Virus (HIV)-positive through early identification of maternal HIV status during pregnancy. Despite this overwhelming success with fetal and infant outcomes, maternal outcomes remain dismal. The purpose of this study was to determine if previously published barriers to HIV treatment adherence affect the perinatal dyad, the postpartum mother, or the exposed infant equally; and to determine if the proposed constructs of structural facilitators or structural barriers affect adherence in the perinatal dyad, the postpartum mother, or the exposed infant. A descriptive and analytic case comparison study was conducted on 100 pregnant women, and they and their infants were followed from entry into the high risk obstetrical clinic with a diagnosis of HIV-infection to 18 months postpartum. All data collected were collected through retrospective chart reviews. Data were analyzed through both descriptive statistics and
logistic regression analysis. Structural facilitators (transportation to clinic, Targeted Outreach to Pregnant Women Act involvement [to provide transportation, emotional support, and/or expedited paperwork], HIV nurse and social worker involvement, medication dispensed [instead of prescriptions given], primary care available onsite, intake paperwork not necessary, and/or previously established and ongoing relationship with case manager) were associated with infant adherence to HIV-related care, and structural barriers (insurance companies, including Medicaid HMOs, that limit access to comprehensive care in the subspecialty HIV clinic or requirement of an individual to link herself with follow-up care, including the requirement of self-initiated case management before clinic appointment is given) were associated with decreased maternal adherence in the postpartum period. Suggestions were made for further research.
CHAPTER 1
INTRODUCTION

Human immunodeficiency virus (HIV) infections continue to increase in incidence and prevalence across minority populations in the United States (Centers for Disease Control [CDC], 2005). In minorities, 64% of transmissions occur in women, 90% of whom were infected through heterosexual contact, with 74% of those infections occurring in non-Hispanic blacks (CDC, 2005). Once infected, the death rate from acquired immune deficiency syndrome (AIDS) for black women in the United States is nine times higher than for Caucasian women (CDC, 2004). Minority adolescent females demonstrate the most rapidly increasing incidence of new infections (Rogers, 2001). The HIV diagnosis usually comes as the result of routine prenatal testing. It is not linked to symptoms experienced or any perceived high-risk behaviors; rather the tests are mandated by public health policy to reduce rates of transmission to fetuses. When a new HIV diagnosis is made, pregnancy is turned into pathology for many minority women. It is particularly hard to engage and retain young postpartum mothers in care, because they do not link well to the current network of adult HIV treatment centers designed to treat men.

HIV-positive women are disenfranchised from both society and treatment facilities due to multiple inequalities. Stigma related to race, income, age, gender, education level, early-onset parenting, sexuality, substance abuse, and HIV infection are present, and a perceived indifference by the medical community is often reported (Ingram & Hutchinson, 1999a). Conventional wisdom within the treatment community
reiterates that adolescents are likely to fail to adhere to treatment because of these barriers (Rogers, Miller, Murphy, Tanney, & Fortune, 2001). In addition, denial of the HIV diagnosis and refusal to act in their own best interest are considered important reasons for continued risky behaviors (Rogers et al., 2001). Yet, at the same points in time, young mothers often care for their exposed infants with vigor and success that is not evident in their own care. This raises a number of questions. Specifically, what are the conditions and attributes that allow young mothers to provide this specialty care successfully for their infants, and what are the barriers that prevent them from participating in self-care? Why are treatment plans that are effective for other populations not effective for minority adolescent mothers?

**Problem Statement**

The health care system has strategies in place to identify HIV-positive women during pregnancy for the purpose of preventing viral transmission to exposed fetuses. Structural facilitators are in place to increase the ability of HIV-positive pregnant women to comply with prenatal and infant care. These facilitators include automatic referral to the HIV treatment team in the High Risk Obstetrical Clinic (HROB) upon diagnosis, immediate access to antiretroviral medication (ART), fast track paperwork to gain emergency Medicaid coverage, field workers from the Targeted Outreach to Pregnant Women Act (TOPWA) to provide support and transportation to clinic and financial appointments, and a registered nurse and a social worker who both attend HROB.

Once born, neonates receive their initial HIV blood test, a two week follow-up appointment at the HIV specialty clinic for results, and ART is dispensed for use at home. Unlike their neonates, postpartum mothers have no automatic referral to the HIV specialty clinic, and have no mechanism in place to ensure they obtain ART prior to
discharge after delivery. Postpartum mothers are often lost to follow-up after delivery until they are pregnant again or until they present for care after the onset of HIV-related symptoms. The interruption of care between delivery and symptom onset has the potential to create the burdens of increased utilization of tertiary health care resources, infant/child abandonment or orphanage, and personal suffering for the mothers. The lack of maternal self-care is attributed in the literature to poverty, education, youth, and clinical depression (Murphy, Wilson, Durako, Muenz, & Belzer, 2001). These maternal characteristics are shared by both the mother and the baby postpartum, but may not always serve as barriers to health care for them both.

**Purpose**

The purpose of this study was to determine if previously identified barriers to HIV treatment adherence affect the perinatal dyad, the postpartum mother, or the exposed infant equally; and to determine if the proposed constructs of structural facilitators or structural barriers are associated with HIV treatment adherence in the perinatal dyad, the postpartum mother, or the exposed infant.

**Hypothesis**

The following two-tailed hypothesis was tested: Maternal depression or other mental illness, proximity of HIV diagnosis, race, income, adolescence, high school education, substance abuse, pill burden, structural barriers to access, and structural facilitators to care are associated with a significant difference in adherence as measured by the laboratory results, missed medication doses, and delayed or missed clinic appointments of HIV-positive pregnant women, postpartum mothers, or their infants.

In order to determine the answer, the following research questions were posed.
1. Are the three groups (postpartum mothers, infants, and dyads) homogeneous with respect to the three outcome measures (laboratory results, medication adherence, and appointment adherence)?

2. Is there a significant relationship between the outcome variables (laboratory results, appointment adherence, and medication adherence) and demographic variables (age, race, mental illness, poverty, new diagnosis, pill burden, high school education, substance abuse) among the three groups?

3. Is there a significant association between the outcome variables (medication adherence, laboratory results, and appointment adherence) and structural facilitators and structural barriers?

4. Is maternal depression or other mental illness, proximity of HIV diagnosis, race, income, adolescence, high school education, poverty, substance abuse, pill burden, structural barriers to access, and structural facilitators to care significantly different as measured by the laboratory results, medication adherence, and appointment adherence in HIV-positive pregnant women, postpartum mothers, or their infants?

**Variables**

The independent variables are maternal depression or other mental illness, proximity (newness) of HIV diagnosis, race, income, adolescence (age), high school education, substance abuse, pill burden, structural barriers to access, and structural facilitators to access. The dependent variables are consistent, but defined differently for each group because the standard of care is different during each period. These outcome measures include laboratory values, percentage of missed doses, and delayed or missed appointments for care.

**Terminology**

For the purpose of this study, the study variables are operationalized as follows.

- **Adolescence**—maternal age less than 24 years at time of conception

- **Delayed care**—HIV-related care not provided during the recommended window of time, or postpartum maternal care or infant immunizations not provided during the recommended window of time

- **Dyad**—unit that includes the pregnant woman and her fetus during the prenatal and antenatal periods
• Education—attainment of a high school diploma, GED, or current enrollment in an equivalent program

• Income—household income less than poverty threshold for the year under investigation

• Laboratory results (dyad)—CD4 and HIV viral loads within expected range based on CDC information for the year under observation

• Laboratory results (infant)—HIV DNA PCRs remain negative at the three recommended intervals, and HIV ELISA /Western Blot is negative at 18 months

• Laboratory results (maternal)—CD4 and HIV viral loads remain within expected range based on CDC recommendations for the period under observation

• Maternal depression or other mental illness—Any psychological diagnosis in the prenatal medical chart that is found in DSM-IV, whether or not treated by medication or therapy

• Missed appointments—appointments missed and not rescheduled >10% of the time

• Missed doses—>10% of ART doses missed by self report at clinic visit

• Pill burden—number of pills/doses per day greater than established norm during the year prescribed (i.e., 5 Viracept and 1 Combivir tabs twice daily = pill burden of 12 tabs/day = average prenatal pill burden from 2000 to 2004; and AZT syrup every 6 hours = 4 doses/day = average neonatal pill burden during entire study period)

• Proximity of HIV diagnosis—determination of whether HIV seropositivity was established during the current pregnancy; a measure of the newness of the diagnosis

• Race—self-reported race (in accordance with federal guidelines)

• Structural barriers to access—Insurance companies, including Medicaid HMOs that limit access to comprehensive care in the subspecialty HIV clinic or requirement of an individual to link herself with follow-up care, including the requirement of self-initiated case management before clinic appointment is given

• Structural facilitators—transportation available to clinic, Targeted Outreach to Pregnant Women Act (TOPWA) involvement to provide transportation, emotional support, and/or expedited paperwork, HIV nurse and social worker involvement, medication dispensed (instead of prescriptions given), primary care available onsite, intake paperwork not necessary, or previously established ongoing relationship with case manager

• Substance abuse—illicit drug or alcohol use during pregnancy
Assumptions

As with any retrospective chart analysis, it was assumed that information contained in the charts was accurate and complete in both reporting by clients and recording by staff.

Limitations

The generalizability of this study is limited to women in social and economic circumstances similar to those of the subjects. Incarcerated and/or toxicology screen-positive mothers at delivery were excluded from this study, as were neonates born with prematurity significant enough to prevent mothers from providing care for their infants. Though foster parents or extended family and friends care for many HIV-exposed infants, this study sought to examine mothers who were primary care providers so that infants and mothers shared the same maternal risk factors at the same times. This limits this study’s ability to describe the circumstances of broken families. Also excluded were the sparse subjects that elected to seek their specialty care from community providers.

Background and Significance

The public health and medical communities have given extensive effort to the protection of fetuses exposed to HIV. The gold standard of care in the United States is the public health initiative to engage the mother-baby dyad in the prevention efforts detailed in the Pediatric AIDS Clinical Trial Group Study Protocol 076 (PACTG 076). This effort focuses on the outcome measure of prevention of HIV transmission to exposed babies. The protocol is overwhelmingly successful in its intent to reduce transmission within the United States, reducing the rate from a natural history of 25-28% (NIH/NIAID, 1999) to about 2% (NIH/NIAID, 1999). The follow-up study, PACTG 219C, continues to look at the health of the exposed infant as it grows into adulthood
(NIH/NIAID, 1999). Neither study considers the outcome of maternal health. Since this research produces such convincing evidence of its efficacy, funding and policy decisions are made based on adherence of clinics to this protocol. In the era of evidence-based practice, the separation of maternal and child health at the time of delivery may unintentionally inform providers’ decisions to cease to address maternal health after delivery. The treatment guidelines continue in a linear fashion along the prevention of transmission, stating guidelines for medicating the neonate with antiretroviral medication, with no recommendations for maternal care after delivery (Figure 1). Mothers cease to be treated by the protocol for their own infections, because they cease to be regarded once they are not carrying babies, and thus not a threat of transmission to children.

Figure 1-1. Routine prenatal screening and care of HIV-positive women
Yoder (2002) contends that participation in the social institutions of medicine and public health can shape values, assumptions, explanatory models, and problem-solving approaches of providers. Altruistic, novice providers who enter the field of HIV treatment and prevention are quickly influenced by the existing treatment culture and explanatory models. Mothers that do not follow-up with their own HIV-related care after delivery are often viewed by providers as being intrinsically unmotivated or self-destructive. Providers often feel that the amount of attention and effort that has been given to mothers during the prenatal period should be enough to retain them in care after delivery. So, their failure is explained away in the literature by describing them as likely to fail based on their intrinsic characteristics (Andersen, 1995) without looking at why that is so. Often, intrinsic factors such as race, income, and age are used to describe away failure, without examination of the context in which the failure occurs. The healthcare community creates this context. Thus, it is important to challenge the existing beliefs and actions of the public health community and health providers who dismiss the mothers as unreachable by looking at the specific circumstances that contribute to their health outcomes. This requires that research take into account structural components that may inform maternal choices.

The public health community determines when treatment occurs, when it does not, and on what priorities research funds are spent. The prevalent themes in the literature that underlie beliefs about HIV prevention, infection, and adherence should be compared to the life circumstances of minority, young females infected with HIV. Before a vulnerable population is dismissed as refractory to help, an earnest scientific
effort should be employed to understand the fit between the system and these mothers. It is imperative to stop dismissing as unreachable those who may simply be misunderstood.

Because of the repetitive claims that minorities cannot or do not adhere to therapy, studies show that minorities are less likely to receive anti-retroviral medications (Cargill, Stone, & Robinson, 2004), though these are the people most likely in need of therapeutic efforts (Basu, 2004). Outside of the United States, populations previously dismissed as unreachable are showing significant adherence through the removal of structural barriers to care. In the central plain of Haiti, adherence to ART heightened in the presence of the concomitant provision of food, opportunity to generate income, and a continuity and parity of health care distribution (Farmer, 2003). To understand the dismissal of adherence potential in HIV-infected young mothers, a look at the history of HIV in the United States is helpful.

HIV first appeared in the United States in the early 1980s as a disease that infected and killed males who were identified as having sex with other males (MSM) (CDC, 2004). Soon after, HIV and the resultant AIDS started infecting and killing intravenous drug users (IVDUs), as well as the female sexual or needle-sharing contacts of both groups (CDC, 2004). HIV in the United States is well established through this history as a disease of stigmatized and vulnerable groups. In 1981, two physicians in New York requested funding from the National Institutes of Health and the American Foundation for AIDS Research to investigate the particular effects of HIV on women. Both grantors rejected the proposals, stating on the return critiques that the effect of HIV infection on women was not an urgent topic for study (Bunting, 1996). Research money and effort in the United States and the world have stayed focused on the treatment of infected men and the prevention of transmission to fetuses, while the epidemic itself has
moved disproportionately to killing young minority women (CDC, 2005). Researchers are now faced with the majority of new infections occurring in minority populations within the United States—populations that likely have different priorities and circumstances than are addressed by the current treatment guidelines. The first step to examining the fit between treatment centers, policy, and young mothers is to explore and describe any differences that may exist in the way the HIV treatment network treats young mothers, and any possible subsequent differences in outcomes.

**Theoretical Framework**

Stigma theory is a middle range theory that was first published in sociology literature by Goffman (1963). Stigma was defined by the Greeks as a bodily sign of a moral flaw Goffman (1963), and was a common concept in the field of social psychology in the 1960s. It was developed into a sociological theory to explain the causes of discrimination in society (Goffman, 1963). Concepts in the theory are the stigmatized attribute, discredited state, discreditable state, stigma, and discrimination (Figure 2). These concepts are incorporated into the theoretical framework of this study, along with four additional concepts that begin to allow for an individual’s response to being stigmatized. Goffman’s (1963) stigma theory is comprised of the following relational statements:

- A stigmatized attribute may lead to discredit.
- Discredit causes stigma.
- Stigma justifies discrimination.
- Discrimination then occurs.
- Discrimination becomes part of an individual’s or group’s environment, the effect of which may increase the stigma experienced.
What happens if a decision is made not to discredit someone with the potential for a stigmatized attribute? It is possible to confer on them protection from the already stigmatized source of this potential stigma. One of the purposes of stigma is to separate normals from the undesirable outcome, or the risk of becoming undesirable. One way that normals distance themselves from perceived risk is to blame stigmatized individuals and groups for having the very trait that renders them stigmatized (Goffman, 1963). Because groups are already blamed for being HIV-positive, other groups that are at risk of becoming infected by these flawed individuals would logically be viewed (intentionally or unintentionally) as victims.
It is plausible that there is an actual protective effect of being perceived as a victim, as much as there is a harmful effect of being perceived as stigmatized or flawed. In this study, a model is proposed (Figure 3) that is reflective of both sides of a potential stigmatizing attribute—one that reflects possible positive and negative outcomes, simply dependent upon how the health care community and health care policy makers regard the individual or group at entry into care.

Figure 1-3. Proposed revision to stigma theory, as adapted from Goffman (1963)
Concept Definitions

- Stigmatized attribute—Characteristic that reduces a person from “whole and usual to discounted and tainted”; and that may be a perceived physical flaw, character flaw, or tribal membership (Goffman, 1963). In his original work, examples of physical flaws were disfigurement or blindness; examples of character flaws would be homosexuality or being a convicted criminal; and examples of tribal flaws would be a trait passed through family or tradition, such as skin color or religion.

- Discreditable state—State in which an individual with a stigmatized attribute that can be hidden exists. Hiding an attribute such as HIV infection prevents being discredited and possible stigma. The state involves increased stress and worry of being discovered.

- Discredited state—State in which an individual exists when a stigmatized attribute is known to normals.

- Stigma—A belief or an attitude that a person is less than human that is constructed and held by normals as justification for discrimination, or a situation in which an individual is denied full social acceptance (Goffman, 1963).


- Protected class state—Membership in a group that has a stigmatized attribute, yet is viewed as a victim of stigmatized individuals instead of as a stigmatized individual.

- Diminished health outcome—Final health status resulting from failure to receive health care and support to the extent they are available for individuals with similar medical conditions.

- Increased protective effort—Structural facilitators outnumbering those available to other individuals and groups with the same stigmatized attribute; structural barriers are less than those encountered by other individuals and groups with the same stigmatized attribute.

- Optimized health outcome—Final health status resulting from best possible access to health resources and support as compared to individuals with similar medical conditions.

Operationalized Empirical Indicators

- Stigmatized attributes—Racial minority, aged 15-23 years, pregnant, HIV-positive, income below poverty level, education below high school level, documented history of drug or alcohol use during pregnancy, or a documented history of mental illness.
• Discreditable state—An HIV-positive mother who does not disclose her diagnosis to providers and/or to her community, or an HIV-exposed fetus or infant whose status is either unknown or is newly known upon disclosure of mother’s HIV status.

• Discredited state—A pregnant woman or mother whose HIV-positive diagnosis is known to providers and/or her community.

• Stigma—health provider and/or minority community beliefs and attitudes that HIV-positive females should not reproduce, are to blame for their infection, and are less valuable than their HIV negative counterparts. Since stigma is defined as a feeling or an attitude, it is not measured in this review of medical documentation.

• Discrimination—Absence of services available to others that facilitate participation in HIV-related care or presence of policies that delay or prevent participation in HIV-related care (specifically listed under variable definitions).

• Class protective effect—Presence of services that facilitate participation in HIV-related care or absence of policies that delay or prevent participation in HIV-related care (specifically listed under variable definitions, structural barriers and structural facilitators).

• Diminished health outcome—Missed appointments, high viral loads and/or poor CD4 cell counts by laboratory measure, or missed doses of antiretroviral medications.

• Optimized health outcome—Adherence to recommended appointments, therapeutic viral loads and CD4 cell counts by laboratory measure, and adherence to antiretroviral medications.

Though HIV-related literature is peppered with Stigma Theory, other reasons for treatment failure prevail. Most studies focus on health behavior theories that emphasize individual or intrinsic empowerment. Many studies detailed in the next chapter describe intrinsic qualities that make individuals likely to fail treatment. No study was identified that specifically measured the role of structural or extrinsic barriers to care. It may not be just the labeling or stigma that keeps HIV-positive mothers out of care, but rather the preferential treatment others may receive in their presence if these same mothers are denied equal treatment.
CHAPTER 2
REVIEW OF THE LITERATURE

Purpose

The purpose of this study was to determine if previously identified barriers to HIV treatment adherence affect the perinatal dyad, the postpartum mother, or the exposed infant equally; and to determine if the proposed constructs of structural facilitators or structural barriers are associated with HIV treatment adherence in the perinatal dyad, the postpartum mother, or the exposed infant.

Perinatal Transmission

Positive effects on fetal outcomes (HIV status) were reported by the first pediatric clinical drug trials if pregnant HIV-infected women took zidovudine (AZT) during the course of their pregnancy and delivery. The odds of an infected baby being born to an infected mother decreased from about 30% to about 2% with the use of AZT (CDC, 2004). This was a landmark finding for prevention of pediatric AIDS, and was viewed as the end of AIDS in children. Since children would no longer contract HIV from their mothers, the reasoning followed that there would no longer be pediatric HIV in the United States. Many states began to require HIV testing of pregnant females for the protection of the fetuses, and thus the large cohort of infected, minority, pregnant adolescents and young adults continue to be uncovered through diagnosis during pregnancy (CDC, 2004). Existing literature did not reflect the real risk that without changing social and economic circumstances, these same HIV-negative babies and their
friends would grow into adolescents and acquire their own HIV infections because the same social and economic challenges that plagued their mothers now place them at risk. Perinatal HIV literature has an overwhelming focus on the prevention of HIV-infection in the fetus/infant.

**Highly Active Anti-Retroviral Therapy**

It is well established that aggressive anti-retroviral therapy, commonly referred to as highly active anti-retroviral therapy (HAART) increases both the duration and quality of life (Rogers, 2001). Implementation of HAART at the clinically indicated time is the standard of care for infected individuals. An entire subset of social science research focuses exclusively on ways to increase adherence to HAART. Models have been developed to assess readiness and stage change for maximum success with therapy (Glanz, Rimer, & Lewis, 2002). In fact, current treatment guidelines strongly recommend that HAART not be initiated on patients until they demonstrate a readiness to comply with therapy for the long term (Steinhart, Orrick, & Simpson, 2002, p. 58). This recommendation is based on what is viewed as best for the patient and society. Partial compliance or short duration therapy often results in mutated viruses that are resistant to available medication (Steinhart, Orrick, & Simpson, 2002, p. 103), and multiple drug resistant strains of HIV present insurmountable treatment obstacles, increasing the burdens of both cost and mortality to society. The sentinel inconsistency in the guidelines is that the only demographic for whom readiness is not assessed, and patient-centered counseling above and beyond the required post-test (results) is not the norm, is pregnant females (Steinhart, Orrick, & Simpson, 2002, p. 58). According to the theories discussed below, these are the most personally at-risk of the infected population related to both their behavior and biology.
The only scientifically validated risk factor for contracting HIV is engaging in any activity that exchanges infected bodily fluid with someone who has HIV (termed high risk behaviors) term (Steinhart, Orrick, & Simpson, 2002, p. 13). Since secondary prevention (limiting the spread of HIV by identifying those already infected) is the prioritized funding goal for HIV, the question to answer is why certain groups engage in high-risk behaviors more often than others. Basu (2004) found that the top epidemiological predictor for HIV worldwide is a low-income level. It is this low-income level that decides the context and conditions of sexual behaviors. The poor have an increased risk of exposure to pathogenic situations, whether sanitation, crowding, or in this case, the presence of more HIV-infected contacts is the cause. In the United States, being black is considered a risk factor for HIV, because being black is often used interchangeably with the socioeconomic variable of being poor. Nazroo (2003) argued against being black as a risk factor for disease by showing that after income adjustment, health disparities within the United States leveled considerably. The balance of the difference may be attributable to experiences and awareness of racism (Nazroo, 2003).

Krieger (1994) asserts that population patterns of health stem from economic and social activities and inequalities. Behavior models that are the backbone of health sciences assume individual agency that may not exist without public health efforts to identify and remove barriers. Often, the community of scientists that ration resources to the HIV-infected community disregards or negatively regards individuals who are in the wrong group at the wrong time. Basu (2004) recounts two studies, one in which a miner explains the context of his high-risk recreational behavior (his profession has an injury rate of 42% and he is never certain he will live through his work day), and one in which
prostitutes complain of their lack of opportunity. The miner is labeled by the psychologists as “in denial” and tagged with a “low self-esteem.” The researchers label the prostitutes as “liars” who are denying their own agency when they claim that prostitution is the only source of available income. Basu (2004) calls AIDS the symptom in these situations, not the disease.

**Adolescent Adherence**

A review of the literature was conducted using the CINAHL and Medline databases dated 1997 to 2004 with a limitation to English language. Keywords “adolescent,” “adherence,” and “HIV” were utilized. Findings were limited, and of those, few reported successful methods of adherence. Most literature reported reasons for failure instead of ways to promote adherence. Though multiple centers specialize in adolescent HIV identification and treatment throughout the country, only one group of providers have joined to formalize, test, and publish findings. Members of the REACH Project (Reaching for Excellence in Adolescent Care and Health) comprise this group (Murphy et al., 2001).

No research conducted by individual providers was identified in the literature. This is probably related to the federal mandate that HIV funding to go to sub-specialty treatment centers, and the resultant tendency of uninsured and underinsured youth to seek care at these centers. Even with sub-specialty care, adolescence and motherhood remain turbulent times in the lives of HIV-positive women. Pinch (1994) discusses the vulnerability of adolescents in particular, stating that the invincibility perceived by adolescent girls makes them a special concern with regard to their own HIV infections.

An additional concern is the inability for many adolescent females to problem-solve due to psychological immaturity and incomplete educations (Pinch, 1994).
Looking at the theoretical perspectives to adherence to treatment in HIV-infected adolescents, models in the literature generally discuss adolescent development and behavior theories appropriate to reach adolescents and affect desired outcomes. As mentioned earlier, one program of researchers in the United States has committed themselves to researching the specific needs of adolescents with HIV infection.

The group of providers most often seen in the literature is physicians who provide care at 15 clinics in 13 major cities throughout the United States to form the REACH Project. Their findings report a strong association between medication adherence and reduced HIV viral loads (Murphy et al., 2001). Findings also showed less than 50% of subjects reported acceptable adherence to their treatment regimen, and that adherence seems to be a serious problem among HIV-positive adolescents (Murphy et al., 2001). The researchers cited both ease of medication use, also known as decreased pill burden, and treatment of depression as two important issues to be addressed when treating adolescents (Murphy et al., 2001). Though the REACH Project providers come closest to addressing the population of pregnant adolescents, their findings do not provide separate statistics on pregnant adolescents, nor do they suggest interventions specific to the needs of pregnant adolescents.

In the analysis by Murphy et al. (2001), strong social support was reported as necessary to adherence, and a linear decrease in adherence was noted when regimens became more complex. This is not surprising, though it is important to note that regimens for pregnant women are geared toward fetal benefit, and do not usually take pill burden issues into consideration. This is another possible explanation for treatment failure. This lack of consideration of maternal needs indicates a failure to consider barriers to maternal long-term survival.
A subset of REACH providers in Los Angeles performed a simple survey of 31 HIV-positive youth from their clinic to identify factors associated with adherence (Belzer, Fuchs, Luftman, & Tucker, 1999). By self-report, 22% of the youth reported “I forgot” as the reason for missing ART, another 15% reported depression, and 43% reported “too many pills,” though the actual pill burden was not reported by the authors for analysis (Belzer et al., 1999).

At one site the REACH providers developed and tested a program to address adherence problems in adolescents called Therapeutic Regimens Enhancing Adherence in Teens (TREAT) Program (Rogers et al., 2001). The program includes education on benefits of compliance, psychological assessment and support to develop readiness for therapy and to address depression, and tools and reminders, such as signaling watches and pagers (Rogers et al., 2001). Rogers et al. (2001) released a description and preliminary results of their adolescent adherence program based on the Stages of Change Model discussed below. While theoretically, this program and approach should work to increase adherence, it has not been shown to be effective in their cohort in the short term. Their findings indicated less than 40% of participants were adherent to HAART, despite intense interventions. Their recommendations include avoidance of the harmful effects of premature prescription of HAART, further suggesting that the degree to which youth accept their diagnosis predicts success on HAART (Rogers et al., 2001). Though not discussed by the authors, this recommendation was not extended to pregnant adolescents because of secondary prevention policies.

In addition to depression and forgetfulness, Futterman (1999) cites distrust of medications and the medical establishment among teens of color (94% of infected adolescents) as a reason for adherence problems. Finally, in a study yielding contrasting
results, two pharmacists conducted a study of 25 patients, ages 9-21 years using a pager as a reminder for medication doses over a three-month period (Todd & Miller, 2000). Their findings showed that compliance improved anywhere from 45-50% from baseline, using only self-report as a measure. These reported increases in adherence were supported by serologic improvements including lower viral loads and higher CD4 counts (Todd & Miller, 2000).

In summary, there exists a paucity of research addressing compliance improvement in adolescents. No research focuses specifically on the issues faced by adolescent mothers. Much of what was identified focused on the assessment of “readiness,” or psychological measurements to determine if a youth was ready to start taking medications based on whether they were willing and able to comply with medication therapy, thereby reducing self harm over time in the form of ART resistance. Pregnant HIV-positive teens get no assessment of “readiness,” as the focus is on the health of the fetus. Nothing addresses continuation of therapy when the teens are started on ART precipitously and without psychological preparation or acceptance of their diagnoses.

When it comes to individual adherence, most researchers ground their studies in health behavior models. Willey et al. (2000) used the Stages of Change Model, or Transtheoretical Model to assess why patients fail to take medications as prescribed. They studied 161 HIV-infected patients using self-report of compliance and electronic monitoring of adherence (electronic reminders and dose counters), and compared their existing stages of readiness to comply with their actual compliance behavior. The assumption in this study is that prescribing HAART is tantamount to prescribing a lifestyle change, and should not be done without assessing the readiness of the individual...
to accept this proposed change. For pregnant girls in particular, no such preparation is made. The assumption is that the girls must change for the sake of their fetuses, regardless of readiness. This is one explanation of the failure of maternal treatment continuity. Their findings showed that reminders and dose counters, mainstays in the adherence community, do not work if participants have not advanced to the action and maintenance stages of change.

**Adherence in Other Marginalized Groups**

Tross (2001) published the findings of her ethnography of inner-city Hispanic women within one zip code in New York City. Because of the limited geography and comprehensive techniques, she draws a vivid picture of the barriers to sexual power and health negotiation for these women. She found that despite high-risk lifestyles and knowledge of HIV, none of the women perceived themselves to be at risk. She also documented the absence of discussion of sex or HIV between these women and their partners. According to participants, such discussions at times ended with violence (Tross, 2001). Methodology was comprehensive in this study, utilizing the Community Identification Process (CID) and included a review of community records, individual interviews, and focus groups. Methods included identification of gatekeepers, in this instance, the owner of a bodega and the owner of a laundromat. In both cases, the community identified self-made women of substance in the community as leaders. Four different levels of participants were identified: key participants, system interactors, project staff, and the gatekeepers. This body of work contributes greatly to the sparse body of knowledge regarding women with HIV by applying the inductive approach to HIV prevention within a small community.
Specific interesting findings include the concept of support groups as a “whitey thing,” with a preference shown to provide support where women already go—the supermarket, daycare, schools, and the laundermat. The women also expressed the desire for a female condom that could be applied before engaging in foreplay or sexual activity, and removed after her male partner has left. This illustrates the awkward nature of trying to negotiate safer sex with intimate others in the community. These findings support the idea of social marketing to change the attitudes of a community, as individual change is predicated on community boundaries. They also support listening to group feedback on the kind of care in which they would participate.

The Henry J. Kaiser Family Foundation (1999) also sought to provide a comprehensive description of a “community” by conducting interviews and focus groups on “higher risk” teens and their providers. Though the study lists no specific methodology, it is ethnography-like in its scope. The study included groups with demographic characteristics representative of overall HIV prevalence, so there is not a preponderance of African American female adolescents. Still, there are 30 females, and about half are African American. Again, despite repeated high risk behavior and a cognitive understanding of what constitutes high risk, these adolescents do not view themselves as being personally at risk. It is the only study specifically addressing qualitative content of adolescents and HIV. The point is also advanced that teens themselves express a feeling of hostility and judgment from the healthcare system, and state “teen-friendly” care is a requirement for them.

One interesting finding is the concept of using condoms to “protect” oneself from a sexual partner. Teens do not view sex partners as unclean or dangerous, and therefore do not use condoms for “protection” (Henry J. Kaiser Family Foundation, 1999).
Different messages are either effective or fall on deaf ears, depending on how the population feels they are regarded, and the context into which the message is received.

**Stigma Theory and HIV**

Many researchers have described the conditions experienced by HIV positive people as being consistent with Stigma Theory (Ingram & Hutchinson, 1999a). It has been applied to explain how the health of mothers is overlooked in the interest of their fetuses. Taylor (2001) reported that sick women are differentiated from well women during pregnancy by the mere diagnosis of HIV infection. Bunting (1996) noted that the ability to disregard the needs of mothers is supported by stigmas that render her discounted and tainted. Fathers, the primary source of infection for these mothers, are notably absent from vertical transmission literature as a cause of infection for infants (Pinch, 1994). Similar to feminist theory, Stigma Theory defines the community of HIV-positive women as deviant, or “other” (Taylor, 2001). Their societal status places them at risk for early pregnancy, and their early pregnancy leads to their HIV diagnosis, this process of diagnosis during pregnancy is explored in the literature of stigma theory.

Taylor (2001) notes that “sick” women are separated from “well” women during pregnancy by the mere diagnosis of HIV infection, regardless of whether or not symptoms are present. She comments that this earns them the label, “Seemingly healthy, but doomed.” She takes care to separate the patient’s emic viewpoint of feeling well until medications (with their unpleasant side effects) are started, from the medical profession’s etic view of having an uncontrolled infection until medications are started. How the concepts of medication, illness, and wellness are conveyed to these young minority females has a lot to do with the way females communicate in general. A need for connection is inherent in females (Pinch, 1994). Females have a need to be linked to
a supportive personal network more so than males. Knowing, including knowing about self and HIV-infection, is generally based on passively received knowledge or subjective knowing for poor women (Pinch, 1994). “Facts” are defined to these women as what political leaders and health care providers say they are (Pinch, 1994). This means that in the absence of empowering these girls, advice rendered to these mothers should be with the full understanding of their position and vulnerabilities.

Although Taylor (2001) discusses both the Health Belief Model and the “rational choice model,” she seems to suggest the rational choice model is the dominant view in HIV treatment communities. This model, though not elaborated in her writing, implies that the medical community assumes that patients will adhere to prescribed treatments and prevention practices once educated about HIV infection, simply because of medical advice. It does not take into account any of the concepts discussed as barriers to adherence in other studies. According to Taylor (2001) one primary barrier is the need to hide the diagnosis because of stigma. If the mothers seek treatment, the child may be labeled as infected, whether or not it is actually is. In this sense, by continuing her own treatment, the mother is putting her child at risk of stigma. According to Bunting (1996), the danger the mother represents to society though infecting innocent and unborn babies rationalizes the choice to ignore her particular health concerns. She becomes stigmatized, with discrimination by the health care system as a consequence Bunting (1996).

Qualitative researchers have done the most work in describing the stigma of HIV. Poindexter and Linsk (1999) conducted one-time semi-structured interviews on 19 older African American women who were caregivers to family members with HIV/AIDS. Though the subjects are HIV negative and older, they are members of the African
American culture and can speak to the context of being (or perceived as being) HIV-positive in this community. This is the only study to look at the attitudes of African Americans toward each other in regards to HIV infection. The point of the study was interesting; in that the investigators were interested in the burden these women bear as elders and caregivers. Their overall findings suggest that stigma should be addressed as part of social work intervention. Of particular interest in the findings was that many of these women rely on church for comfort, but do not disclose to any members or their pastors that they have an HIV-positive family member. This comfort seems to be regarded as contingent on secrecy and vulnerable to the threat of withholding comfort if the secret is known. Three participants talked of their own discrimination of HIV-positive community members—until one appeared in their family. One participant viewed this as punishment from God for past discrimination.

Poindexter and Linsk (1999) review Goffman’s stigma theory, summarizing the three related types of stigma: associative stigma (ascribed to those attached to stigmatized persons—also called courtesy stigma), internalized stigma (acceptance of society’s appraisal of one’s reduced worth), and stigma management (being aware of real or potential reactions of others). Methodology consisted of semi-structured questions such as, “Tell me a story about how you or your family members have had negative responses or have experienced discrimination about AIDS.” Data collection included field notes, observations, and researcher comments. Content was then coded and analyzed, with results revealing that the majority of African American women acknowledge stigma, but avoid it personally by carefully guarding disclosure of the HIV status of their family members.
Another study looked specifically at the emergent fit of Goffman’s stigma theory to a grounded theory approach to HIV positive mothers. Ingram and Hutchinson (1999a) published their discovery of an emergent fit of extant theory to their findings. In their grounded theory approach to the mothering experience for HIV-positive women, themes related to stigma kept arising. Through a review of existing literature on this phenomenon, Goffman’s theory seemed appropriate. The details of the grounded theory study are listed separately below, but the themes that kept arising related to stigma are privacy, passing, and covering in clinic. Stigma is an unanticipated difference that discounts other attributes of an individual and causes the rejection of others (Ingram & Hutchinson, 1999a). In relation to parenting, mothers also reported that this stigma spread to their children, whether or not they were infected. Quotes such as, “No one would touch my children” were common. Findings included leaving “double lives” behind a “facade of normal mothering.”

The concept of passing pertains to something that is not apparent being concealed. The experience of appearing normal, with all of its benefits, is mitigated by the constant threat of exposure and losing the benefits. The women going to church for the benefit of support without expressing why they needed the support for fear of losing the support is a good example. The need to pass is evidenced by the unwillingness to have AZT in their homes because of its name recognition (Ingram & Hutchinson, 1999a). Covering is the act of managing social tension and distracting attention away from the stigmatizing quality (Ingram & Hutchinson, 1999a). Examples from the study include lying about reasons for medication (i.e., back pain, cancer) and referring to visits to the doctor as “shopping trips.” In another, a woman struggling with weight loss from her medications told her co-workers she was on a strict weight loss program. Their response
was that, “I would sure love to lose weight the way you did.” She states she thought, “No, you most definitely would not.” The women believe that lies are justified as a means for survival (Ingram & Hutchinson, 1999a).

**Psychological Distress and HIV**

Because of the well-documented link between depression and a suppressed immune system, Pinch (1994) theorizes systematically oppressed adolescent females to be at a higher risk for rapid HIV disease progression. Looking at the effects of stress becomes important to this issue. Smith et al. (2001) use the Stress Process Model to explain psychosocial functioning in African American recent mothers. The domains of this model include stressors, coping resources, close relationships, coping responses, and psychological distress. They found that though adherence and treatment literature assumes both comprehension of and focus on the diagnosis of HIV, many of their subjects rated money as a greater concern than HIV infection. This appears important, as it addresses the concept of immediacy in these women. HIV infection is an arbitrary concept with no immediate manifestation (symptoms); whereas poverty has daily implications for housing, food, clothing, and transportation. Smith et al. (2001) concluded this special population needs interventions to improve their social and economic conditions, with interventions to address their HIV infection tailored to their strongest measured resources.

Murphy et al. (2001) agreed with this association between psychological distress and health risk behaviors, and sought to apply this theoretical perspective to adolescents with HIV. They utilized Jessor’s Problem Behavior Theory as their theoretical framework. This theory focuses on three major concepts: behavior, personality, and environment (Murphy et al., 2001). Their study suggests that higher levels of depression
predict increased risk taking behaviors, despite what they describe as youth-appropriate risk reduction counseling. Anxiety related to health status, i.e. HIV infection, actually increased the maladaptive coping behaviors of substance abuse and unprotected sex. This could likely be studied in direct relationship to medication adherence with the same results. This finding suggests that medical interventions in the absence of addressing depression and environment are likely to fail.

Mellins, Ehrhardt, Rapkin, and Havens (2000) appear to agree with the above models in their study of psychosocial factors and adaptation in HIV-infected mothers. Though no explicit framework is cited, the concepts of environment, stress, protective factors, and depression are listed. They found that mothers with HIV have additional stressors of racism, isolation, poverty, discrimination, and single motherhood. These make them more disposed to diagnoses of depression and post-traumatic stress disorder. They also found that relationship breakup, assault, abuse, and removal of children played a major role in causing these disorders. Ironically, some providers offer the fear of removal of exposed infants as the primary reason mothers adhere to treatment protocols. This is proffered as an explanation by some of the staff in the clinic to be studied, though no legal precedent for the removal of exposed babies is established in Florida.

**Minorities and HIV**

bell hooks (2003) describes an early movement within the African-American culture toward increased self-esteem and self-love, regardless of external events. She describes a revolution where success was defined as the ability to value and revere oneself despite the presence of dehumanization. This movement, largely led by males, also demanded that men regain their historical position of being “revered by their women.” By definition, this would make the subjugation of women necessary for the
advancement of men. Not only is it undoubtedly frustrating for men to be expected to appear intact and invincible in the presence of ongoing subjugation, but in a people struggling for power, domination of women is the only area in which this is easily achievable. This leaves black women in the terrible place of being less regarded even within the culture that should provide harbor from discrimination.

Wilkinson (1999) states that in places with more income inequality, more deaths can be attributed to violence. Nondisclosure of status before unprotected sex, and the refusal to wear condoms are both acts of violence. Though the attributable cause of death may be pneumocystis pneumonia secondary to AIDS, the primary cause of death is an act of violence. Wilkinson (1999) further elaborates with reference to the “shame rage spiral,” where in effect, hostility mounts in the presence of unacknowledged shame. Many black men are infected during incarceration, and this is a reasonable explanation for black men feeling entitled to not disclose their HIV status to their female partners upon release from prison. This, combined with the expectation of machismo, explains why impregnating a woman (sign of virility) is the bragging right of many men, without regard for the current or future health of the woman or the fetus. Farmer (2003) makes a similar argument by stating that people subordinated by their social superiors and threatened with humiliation, attempt to regain their sense of control by asserting authority and control over those below them. The power imbalance between men and women in minority communities is discussed extensively in the literature.

Beatty, Wheeler, and Gaitner (2004) conducted a review of HIV prevention literature to look for inclusion of African American subjects with the intent of making recommendations for the development of more effective prevention strategies for this group. They reported a lack of culturally based theory to guide the existing research and
at the same time suggested that black Americans are too large and diverse a group to be placed within one cultural definition. They found that research aimed at behavioral lifestyle change was over represented in the literature, with the Health Beliefs Model, the Theory of Reasoned Action, and the Transtheoretical Model of Behavior Change being most commonly used. It was reported that often, even if included as subjects in a study, minorities were not later broken out and analyzed as a separate group. They suggested that models sensitive to different groups of minorities be developed and that not all effort should be extended to individual change, as individuals do not always have the control necessary to initiate changes. Women rarely have control over the elements of survival sex, and childhood sexual abuse and unwanted adult sexual activity are both reported as risk factors for risky sexual behavior, and for substance abuse that leads to risky sexual behavior (Cargill, Stone, & Robinson, 2004).

The idea that any of this behavior is fully volitional is a stretch. Lynch, Kaplan, and Salonen (1997) question the popular theories now that attribute health behaviors to the choices that individuals make, because they make health behavior both individual and volitional; neither of which are usually the case for women at risk for HIV. The theories predict that if groups at high risk for HIV infection are simply told what behaviors to avoid and why, they will stop the behaviors. Their findings showed that while there is correlation between current SES and health behaviors in adulthood, there also exists correlation between health behaviors in adulthood and SES at specific temporal milestones throughout childhood. In other words, behaviors are in some way linked to parental SES—an influence on behavior that neither an individual nor a provider could go back in the past to change (Lynch et al., 1997). This is a strong argument for increased economic parity in society, though it would be unattractive to most public
health providers and planners specifically because it lacks agency, even on the part of programs. Programs act in the present and occasionally for the future; never in the past. The effects of SES parity now, even if attained, would not be measurable for a lifespan. Since program evaluations must measure changes each funding cycle, this would never happen.

In their recent study, Cargill, Stone, and Robinson (2004) found evidence that minorities are less likely to receive antiretroviral medication therapy (ART) even if the guidelines indicate it as the standard of care. Often this is attributed to the provider’s sense that the patient will be unable to adhere to care. Basu (2004) observed that if ART were reserved only for those who seem most likely to adhere to regimens, then only those least likely to be in need of ARTs would receive them.

This is not the only recent work to support the idea that the behaviorist theories are shortsighted. Aynalem, Mendoza, Frederick, and Mascola (2004) found in their study of pregnant women who refused HIV-testing reported that 4% of women had to seek their husband’s permission prior to consenting to the test. This clearly negates personal agency. Many others feared stigma, discrimination, disclosure, violence, or had a lack of trust in the provider to prevent any of these. The authors fell short by suggesting that through additional education and time to trust the providers, that many of these women would change their minds. This seems naïve in that it addresses none of the structural or domestic problems that were identified as driving the refusal in the first place.

Another commentary on the behavior theories is the finding of Whyte, Standing, and Madigan (2004) that there was actually a positive correlation between HIV-related knowledge and high-risk sexual behaviors in African American women in the southeast. Income, age at first sexual encounter, number of partners, and education level were all
analyzed, with only education level having a significant impact on behavior. This shows that the population-specific messages are reaching the community; they are just not having an impact on behavior. Ebrahim, Anderson, Weidle, and Purcell (2004) analyzed data from the 2001 Behavioral Risk Surveillance Survey. They found that though African Americans had a higher rate of having ever been tested for HIV, they had a lower level of knowledge about available treatment. Overall, even those who had been tested were not aware that treatment for infection now exists. This shows the durability of the targeted messages to avoid contracting this fatal disease, and about it being a death sentence. The danger of targeting these types of messages at a community already devoid of hope for the future is that the messages ablate any hope for a future once a person is diagnosed with HIV.

Positive Adaptation

Despite the grim outlook, some women, devoid of many identified barriers, do exceptionally well with their HIV diagnoses. Speigel and Schrimshaw (2001) conducted a series of two semi-structured interviews that they then subjected to thematic analysis. The subjects were HIV-positive women who claimed to have had positive changes as a result of their diagnoses. Exclusion criteria included intravenous drug use, and the average age was 36 years, with a sample size of 54. One-third was African-American. The mix of subjects is not reflective of HIV-positive women in general, so the findings are not generalizable. These women, unlike any other described in literature or seen in personal experience, describe HIV infection as a catalyst to resolving their relationship conflicts, a queue to enjoy life, and a step to becoming strong advocates for themselves. While there may be some merit to the idea advanced that perceptions of positive outcomes may imply positive outcomes—certainly supported in psychoneuro-
immunology literature, it is not consistent with the findings closer to the population of interest.

Dunbar, Meuller, Medina, and Wolf (1998) conducted similar semistructured interviews in the hopes of supporting their previously created model relating to positive adaptation. They conducted interviews with 34 women in a study that also appears to be nongeneralizable because of the geographic demographics of their convenience sample. Unlike HIV-infected women, their participants were almost half Pacific-Islanders; college educated, and had an average age of 36. They found five components that supported their model of adaptation: reckoning with death, life affirmation, creation of meaning, self-affirmation, and redefining relationships. All of these processes they described require reflexivity and a level of acceptance of diagnosis that far exceed that documented in the target population of this paper. However, the concept of understanding personal growth, as a precedent to effective coping is consistent with previously explored stress models.

Neither of these studies published clear descriptions of their data analysis. Both of these studies suggest a population that has adjusted to their diagnosis, presents for care, acts in their own best interest, and is therefore largely incongruent with the population of interest. Identifying the barriers faced by minority HIV-positive adolescent mothers from this differently adjusted population may be of some value. Studies addressing barriers to adherence provide some explanation as to the contextual differences experienced by these groups.

**Mothering by HIV-Infected Women**

Ingram and Hutchinson (1999b) described their grounded theory study in another publication in greater detail. The purpose was to describe the mothering
experience of HIV-positive women. The goal was to understand actions in the context of their beliefs. A sample of 18 HIV-positive mothers aged 18-44, half of whom was minority, was subjects of extensive interviews. Using a grounded theory technique, a basic social psychological process (BSPP) of defensive mothering was discovered. The obvious connection to stigma is described in one woman’s comment, “Everything you do in your life you have to worry about if someone is going to find out. It is hard. You have to watch everything you say and do.” They concluded that stigma provides the context of HIV-mothering, and sets the stage for defensive mothering (Ingram & Hutchinson, 1999b). Mothering consists primarily of ways to protect the child from both herself and society’s prejudices. This relationship, that seems to explain a mother’s preference for her child’s welfare over her own, is further explored in another less rigorous qualitative study in the literature.

Andrews, Williams, and Neil (1993) conducted a series of two qualitative interviews: the Norbeck Social Support screen and a substance abuse screen to a sample of 80 HIV-infected mothers. A weakness in this study is that no description of data evaluation was included. No significant themes were identified, and no methodology other than “interviews” was given. Quotes were discussed generally, but not truly analyzed. The two tested screens that could be reported on an ordinal basis were more fully described. When evaluating social support, it was impressive to reveal how many of these mothers relied on young children for emotional support (Andrews et al., 1993). In regards to the medical community, most women expressed distrust. One woman, in commenting on care offered to her HIV-positive son, said “They want to put him on DDI. The AZT is making him too anemic. I’m going to try the DDI dose they want him on first, before they give it to him. My thinking is that he and I are almost the same, you
know, with the same genes, so I’ll know what side effects he’ll get from the DDI” (Ingram & Hutchinson, 1999a). This statement shows a total lack of understanding of the relationship between body surface area and side effects, but more alarming is that her views are built on the foundation of mistrust.

The research reviewed describes the women who are likely to fail treatment, or describes the society at large that stigmatizes and alienates women from caring for themselves. Ample descriptive data were identified that described women who fail treatment, but this data does not differ from the descriptions of women most likely to be infected with HIV. A small but important section of the literature tried to determine how women experienced living with HIV, and allusions were made to perceived judgment and hostility in their worlds at large, including in the HIV treatment community. The next logical step is to gather quantitative data to describe whether or not this perceived difference in treatment is associated with differences in outcomes, because if it is, then modifying the treatment environment will be fundamental to improving maternal outcomes.
CHAPTER 3
METHODS

Purpose

The purpose of this study was to determine if previously identified barriers to HIV treatment adherence affect the perinatal dyad, the postpartum mother, or the exposed infant equally; and to determine if the proposed constructs of structural facilitators or structural barriers are associated with HIV treatment adherence in the perinatal dyad, the postpartum mother, or the exposed infant.

Design

This was a descriptive and analytic epidemiologic case comparison study. The goals were both to describe frequencies of exposures and outcomes in the three groups and to analyze which independent variables best predicted outcomes. All data collected were collected through retrospective chart reviews. Data were analyzed through both descriptive statistics and logistic regression analysis. A convenience sample was obtained through systematic review of the charts of HIV-positive pregnant women in the high risk obstetrical clinic (see Figure 3-1). The study was constructed of 100 maternal cases and 200 comparisons. The 100 maternal cases consisted of postpartum HIV-positive women with the group name “postpartum mothers.” The 200 comparisons were comprised of two groups. One hundred of the comparisons comprised the group “dyad” and consisted of the same mothers as the case group during a different time interval. For this group, data were collected during the prenatal period instead of the postnatal period. The last
100 comparison subjects were in the “infant” group. This group was comprised of the babies born to the dyad group. As such, these infants shared maternal risk factors at the same point in time as the maternal group. The subjects were all patients of the same HIV subspecialty clinic and its affiliated high risk obstetrical clinic. Table 3-1 depicts the distribution of the independent variables for the maternal sample.

Figure 3-1. Subject selection

Setting

This study was conducted at an urban outpatient HIV clinic and its affiliated high risk obstetrical clinic in the southeastern United States. Data were collected through chart extraction without contact with subjects. The clinics are located in an urban
medical complex and are staffed by nurses, physicians, students, and residents. Patients in the high risk obstetrical clinic receive specialty prenatal care for a variety of conditions including HIV seropositivity, diabetes, and epilepsy. The HIV clinic is located in the same complex and is part of the same health system. It is a federally funded (Ryan White) and state funded (Children’s Medical Services/Medicaid) HIV sub-specialty care clinic. Care is provided in tandem by nurse practitioners and infectious disease physicians on an outpatient basis. HIV treatment, psychological support, dietary support, social work support, and primary care are all offered on site, unless specifically excluded by insurance or funding regulations.

Subjects

Sample Selection

Convenience sampling was used to select the sample from eligible dyads. Based on a prediction that 30% of the subjects were in adherence to HIV care, approximately 229 subjects were required given a 0.05 level of significance, the 10 predictors, and 90% power of the test.

Inclusion Criteria

• Subjects were HIV (+) females whose prenatal medical care was provided by the high risk obstetrical clinic at the study site from 2000 to 2004.
• The mother and infant both survived through 18 months postpartum.
• The infant remained in the primary care of the biological mother.

Exclusion Criteria

• Neonatal, infant, or maternal subjects who spent greater than 2 weeks inpatient during the 18-month observation period.
• Neonates and infants who spent greater than 2 weeks outside of the primary care of their biological mothers during the observation period.
• The mother or the baby died before the end of the observation period.
Data Analysis

The Statistical Analysis System (SAS) (Version 9.1) was used for all statistical analyses and for writing the scientific report of the quantitative data. Descriptive statistics were used to obtain the summary measures for all data including a description of the sample characteristics. Descriptive statistics included means, medians, modes, ranges, interquartile ranges, and standard deviations for continuous variables. Categorical variables were statistically represented in frequency distributions, percentage distributions, and graphical illustrations. A p-value of less than 0.05 was considered statistically significant.

To address the major hypothesis of the study, stepwise logistic regression with forward elimination techniques were used to both control for confounders and estimate independent relationships between the predictive variables and the outcome. Logistic regression analysis was also used to explore potential differences in predictor variables between who participated in recommended HIV care from those who did not. All predictor variables were included that had either at least a marginal bivariate association with the outcome variables or for which there was some rationale that the variable may have been a confounder or effect modifier for other variables. This initial model also included hypothesized interaction terms for which stratification analyses suggest potential interactive effects.

The point and interval estimates of the odd ratios of the categorical predictor variables were reported. The hypothesis of homogeneity was addressed by running frequencies. In most cases, Chi-square statistics were presented. In cases where any cell in the 2x2 table or 3x2 table was valued at less than 5, the Fisher’s Exact Test for small samples results was instead used for increased validity.
Procedure

Following graduate committee approval, paperwork was processed to gain approval of the University of Florida Institutional Review Board (IRB-01). Included in the packet was a letter of support from the administration of the study site. Expedited processing was requested and approved, as subjects were fully de-identified for their protection (in compliance with the Health Information Portability and Accountability Act of 1996). This option was chosen because the identifying data omitted was not essential to study outcomes. Subjects were deemed vulnerable because data on mental illness and substance abuse were collected from pregnant, HIV-positive and potentially pediatric subjects. After clearing the University of Florida IRB-01, approval of the study site IRB was also requested and obtained under the same conditions.

Data Collection

Upon approval of the University of Florida IRB-01 and study site IRB, de-identified data were collected through chart extraction onsite at the clinic. The data collection form was constructed using Snap software. The principal investigator personally conducted or oversaw data collection at all times. Each subject was assigned a unique numeric identifier not traceable back to the subject at any time and not recorded any place that contains protected health information (PHI). As the site is a federally funded HIV clinic, superconfidential requirements were already in place onsite. Off-site, de-identified data were transported via password protected laptop computer and transferred to the secure server of the University of Florida College of Nursing. A backup copy of the de-identified data remains in the possession of the Principal Investigator and is stored securely.
Potential Health Risks

There were no physical or psychological risks to subjects of this study. There was no intervention and no contact at any point with subjects. All data collected were de-identified from the outset, eliminating the risk associated with disclosure of HIV status.

Potential Health Benefits

There were no direct health benefits from participation in this study as there was no contact with subjects and no intervention. There were potential benefits to society as knowledge was gained to explain reasons HIV-positive mothers are lost to follow up care at a disproportionate rate. Considering the potential impact premature parental death has on children, families, and society, the benefit of decreasing parental morbidity and mortality outweighs the risk to subjects.

Potential Financial Risk

There was no cost to subjects, no information that would trace back to subjects, and no contact with subjects. Therefore, there was no potential financial risk.

Potential Financial Benefits

There was no reimbursement or compensation of any kind to subjects. Therefore, there was no potential financial benefit to subjects.

Conflicts of Interest

The principal investigator and subinvestigators did not have any conflict of interest regarding this protocol. No benefit, beyond professional and academic development was derived from participation in this project.
CHAPTER 4
RESULTS

Purpose

The purpose of this study was to determine if previously identified barriers to HIV treatment adherence affect the perinatal dyad, the postpartum mother, or the exposed infant equally; and to determine if the proposed constructs of structural facilitators or structural barriers are associated with HIV treatment adherence in the perinatal dyad, the postpartum mother, or the exposed infant.

Description of Sample

The convenience sample in this case comparison study was constructed of 100 maternal cases and 200 comparisons. The 100 maternal cases consisted of postpartum HIV-positive women with the group name “postpartum mothers.” The 200 comparisons were comprised of two groups. One hundred of the comparisons comprised the group “dyad” and consisted of the same mothers as the case group during a different time interval. For this group, data were collected during the prenatal period instead of the postnatal period. The last 100 comparison subjects were in the “infant” group. This group was comprised of the babies born to the dyad group. As such, these infants shared maternal risk factors at the same point in time as the maternal group. The subjects were all patients of the same HIV subspecialty clinic and its affiliated high risk obstetrical clinic. Tables 4-1 and 4-2 depict the distribution of the independent variables for the maternal sample.
### Table 4-1. Number and percent distribution of maternal sample by age and race

<table>
<thead>
<tr>
<th>Age</th>
<th>14-18</th>
<th>19-21</th>
<th>22-24</th>
<th>&gt;24</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>13</td>
<td>21</td>
<td>62</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>AA</th>
<th>Carribean Island</th>
<th>Hispanic</th>
<th>Caucasian</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>40</td>
<td>21</td>
<td>16</td>
<td>12</td>
<td>11</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 4-2. Number and percent distribution of maternal sample by dichotomous variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Yes</th>
<th>No</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental illness</td>
<td>23</td>
<td>77</td>
<td>100</td>
</tr>
<tr>
<td>New diagnosis</td>
<td>62</td>
<td>38</td>
<td>100</td>
</tr>
<tr>
<td>Poverty</td>
<td>67</td>
<td>33</td>
<td>100</td>
</tr>
<tr>
<td>HS/GED</td>
<td>61</td>
<td>39</td>
<td>100</td>
</tr>
<tr>
<td>Drugs or alcohol</td>
<td>4</td>
<td>96</td>
<td>100</td>
</tr>
<tr>
<td>Pill burden</td>
<td>0</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

### Variables

The independent variables are maternal depression or other mental illness, proximity (newness) of HIV diagnosis, race, income, adolescence (age), high school education, substance abuse, pill burden, structural barriers to access, and structural facilitators to access. The dependent variables are consistent, but defined differently for each group because the standard of care is different during each period. These outcome measures include laboratory values, percentage of missed medication doses, and delayed or missed appointments for care.

### Hypothesis

The following two-tailed hypothesis was tested: Maternal depression or other mental illness, proximity of HIV diagnosis, race, income, adolescence, high school education, substance abuse, pill burden, structural barriers to access, and structural facilitators to access.
education, substance abuse, pill burden, structural barriers to access, and structural facilitators to care cause a significant difference in adherence as measured by the laboratory results, missed medication doses, and delayed or missed clinic appointments of HIV-positive pregnant women, postpartum mothers, or their infants. In order to test the hypothesis, the following four research questions were asked and answered.

**Research Question One**

Are the three groups (postpartum mothers, infants, and dyads) homogeneous with respect to the three outcome measures (laboratory results, medication adherence, and appointment adherence)?

An analysis of frequency was used to evaluate this question. Chi-Square statistics and p-values were computed by cross-classifying the variables and groups with each outcome variable.

The results presented in Table 4-3 indicate that the three groups were not homogeneous with respect to laboratory results (Chi-Square=98.82, p=0.0001). Laboratory results were significantly less likely to be in the acceptable range for postpartum mothers (47%) than for infants (96%) or dyads (96%). The result indicated that the three groups were not homogeneous with respect to ART medication adherence (Chi-Square=74.12, p=0.0001). Medication adherence was significantly less likely to be in the acceptable range for postpartum mothers (36%) than for infants (90%) or dyads (92%). The three groups were also not homogeneous with respect to appointment adherence (Chi-Square=57.16, p=0.0001). Appointment adherence was significantly less likely to be in the acceptable range for postpartum mothers (52%) than for babies (80%) or dyads (97%). Table 4-3 depicts the distribution of outcomes in each group.
Table 4-3. Distribution of cases and comparison groups by independent variables of exposure to barriers and exposure to facilitators, and by outcome measures of favorable laboratory results, medication adherence, and appointment adherence

<table>
<thead>
<tr>
<th>Cases</th>
<th>Comparison groups</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Postpartum mothers</td>
<td>Dyads</td>
<td>Infants</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Total %</td>
<td>Yes</td>
<td>No</td>
<td>Total %</td>
<td>Yes</td>
</tr>
<tr>
<td>Exposure to barriers</td>
<td>31</td>
<td>69</td>
<td>100</td>
<td>5</td>
<td>95</td>
<td>100</td>
<td>31</td>
</tr>
<tr>
<td>Exposure to facilitators</td>
<td>6</td>
<td>94</td>
<td>100</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>97</td>
</tr>
<tr>
<td>Favorable laboratory results</td>
<td>47</td>
<td>53</td>
<td>100</td>
<td>96</td>
<td>4</td>
<td>100</td>
<td>96</td>
</tr>
<tr>
<td>Medication adherence &gt;90%</td>
<td>46</td>
<td>54</td>
<td>100</td>
<td>90</td>
<td>10</td>
<td>100</td>
<td>92</td>
</tr>
<tr>
<td>Appointment adherence</td>
<td>52</td>
<td>48</td>
<td>100</td>
<td>80</td>
<td>20</td>
<td>100</td>
<td>97</td>
</tr>
</tbody>
</table>

**Research Question Two**

Is there a significant relationship between the outcome variables (laboratory results, appointment adherence, and medication adherence) and demographic variables (age, race, mental illness, poverty, new diagnosis, pill burden, high school education, substance abuse) among the three groups?

Analysis of frequency and Cochran-Mantel-Haenszel Statistic were used to address this question. The results shown in Table 4-4 indicated that the relationship between laboratory results and age, maternal race, mental illness, poverty, pill burden, and new diagnosis were statistically nonsignificant for each group. The relationship between laboratory results and education were statistically nonsignificant for infants and for postpartum mothers (Chi-Square=4.79, p=0.03). The Cochran-Mantel-Haenszel Statistic indicated an overall significant relationship between laboratory results and education (Chi-Square=4.92, p=0.03). Mothers with a high school education were 2.24 times more likely to have favorable laboratory results (C.I: 1.1-4.6). There was also a
significant association between laboratory results and substance abuse for postpartum mothers (Chi-Square=4.97, p=0.03) and for dyads (Chi-Square=4.78, p=0.03), though there was no significant relationship to infant outcomes. The overall association was statistically nonsignificant.

Table 4-4. Relationship between maternal age, race, mental illness, poverty, education level, substance abuse, and objective pill burden and the outcome measure of laboratory results

|                | Cases | Comparison groups |               | |               |               |
|----------------|-------|-------------------|---------------|-----------------|-----------------|
|                | Age   | Race              | Mental illness| Poverty         | New diagnosis   | HS/GED          | Substance abuse |
|                | Chi-squared | p | Chi-squared | p | Chi-squared | p | Chi-squared | p | Chi-squared | p | Odds ratio | 95% CI |
| Postpartum mothers | 0.79 | 0.85 | 3.02 | 0.55 | 1.09 | 0.30 | 0.40 | 0.53 | 0.22 | 0.64 | 4.79 | 0.03 | 2.24 | 1.1-4.6 |
| Dyads          | 0.85 | 0.84 | 6.25 | 0.18 | 1.72 | 0.19 | 2.05 | 0.15 | 0.25 | 0.61 | 0.21 | 0.65 |               |
| Infants        | 2.55 | 0.47 | 1.72 | 0.79 | 0.01 | 0.92 | 0.54 | 0.46 | 0.25 | 0.61 | 0.21 | 0.65 |               |

The results shown in Table 4-5 indicated that the relationship between medication adherence and age, maternal race, mental illness, poverty, pill burden, and new diagnosis were statistically nonsignificant for each group. There was a significant relationship between maternal education and medication adherence for infants (Chi-Square=4.48, p=0.03) and postpartum mothers (Chi-Square=5.97, p=0.01), though there was no significant association with medication adherence and education for dyads. The overall association of medication adherence and education for groups was statistically significant (Chi-Square=8.07, p=0.005). Medication adherence was 2.49 times more likely to be in the acceptable range if mothers had a high school education (C.I.: 1.32-4.7). There was a significant relationship between medication adherence and substance abuse for mothers (Chi-Square=4.89, p=0.03), but not for dyads or infants. The general association test between medication adherence and substance abuse for the groups was statistically
significant (Chi-Square=5.11, p=0.02). There was no significant relationship between the independent variables and appointment adherence, as shown in Table 4-6.

Table 4-5. Relationship between maternal age, race, mental illness, poverty, education level, substance abuse, and objective pill burden and the outcome measure of medication adherence

<table>
<thead>
<tr>
<th></th>
<th>Cases</th>
<th>Comparison groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Postpartum mothers</td>
<td>Dyads</td>
</tr>
<tr>
<td></td>
<td>x²   p</td>
<td>x²   p</td>
</tr>
<tr>
<td>Age</td>
<td>0.52 0.91</td>
<td>0.42 0.94</td>
</tr>
<tr>
<td>Race</td>
<td>1.74 0.78</td>
<td>4.33 0.36</td>
</tr>
<tr>
<td>Mental illness</td>
<td>1.33 0.25</td>
<td>7.66 0.01</td>
</tr>
<tr>
<td>Poverty</td>
<td>0.60 0.44</td>
<td>1.65 0.20</td>
</tr>
<tr>
<td>New diagnosis</td>
<td>0.39 0.53</td>
<td>0.01 0.98</td>
</tr>
<tr>
<td>HS/GED</td>
<td>5.97 0.01</td>
<td>0.01 0.93</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>4.89 0.04</td>
<td>0.36 0.55</td>
</tr>
</tbody>
</table>

Table 4-6. Relationship between maternal age, race, mental illness, poverty, education level, substance abuse, and objective pill burden and the outcome measure of appointment adherence

<table>
<thead>
<tr>
<th></th>
<th>Cases</th>
<th>Comparison groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Postpartum mothers</td>
<td>Dyads</td>
</tr>
<tr>
<td></td>
<td>x²   p</td>
<td>x²   p</td>
</tr>
<tr>
<td>Age</td>
<td>4.91 0.18</td>
<td>8.70 0.07</td>
</tr>
<tr>
<td>Race</td>
<td>4.09 0.39</td>
<td>3.20 0.52</td>
</tr>
<tr>
<td>Mental illness</td>
<td>2.09 0.15</td>
<td>0.92 0.34</td>
</tr>
<tr>
<td>Poverty</td>
<td>1.46 0.23</td>
<td>0.00 0.99</td>
</tr>
<tr>
<td>New diagnosis</td>
<td>0.26 0.61</td>
<td>1.08 0.20</td>
</tr>
<tr>
<td>HS/GED</td>
<td>1.81 0.18</td>
<td>0.99 0.32</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>3.85 0.12</td>
<td>0.13 0.72</td>
</tr>
</tbody>
</table>

Research Question Three

Is there a significant association between the outcome variables (medication adherence, laboratory results, and appointment adherence) and structural facilitators and structural barriers?

Analysis of frequency and Cochran-Mantel-Haenszel Statistic were used to address this question. The results shown in Table 4-7 indicated that the relationship between laboratory results and structural barriers (insurance companies, including
Medicaid HMOs, that limit access to comprehensive care in the subspecialty HIV clinic or requirement of an individual to link self with follow-up care, including the requirement of self-initiated case management before clinic appointment is given) were statistically nonsignificant for babies and dyads but were significant for postpartum mothers (Chi-Square=5.53, p=0.02). The overall association according to Cochran-Mantel-Haenszel Statistic was not statistically significant. In addition, the result indicated that the relationship between laboratory results and structural facilitators (transportation to clinic, Targeted Outreach to Pregnant Women Act involvement [to provide transportation, emotional support, and/or expedited paperwork], HIV nurse and social worker involvement, medication dispensed [instead of prescriptions given], primary care available onsite, intake paperwork not necessary, and/or previously established and ongoing relationship with case manager) was not statistically significant for each group.

Table 4-7. Relationship between structural barriers and structural facilities and the outcome measures of laboratory results, medication adherence, and appointment adherence

<table>
<thead>
<tr>
<th></th>
<th>Cases</th>
<th>Comparison groups</th>
<th>Odds ratio</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory results</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structural barriers</td>
<td>5.53</td>
<td>1.87</td>
<td>0.64</td>
<td>0.22</td>
</tr>
<tr>
<td>Structural facilitators</td>
<td>3.38</td>
<td>0.13</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Medication adherence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structural barriers</td>
<td>4.23</td>
<td>0.15</td>
<td>0.58</td>
<td>0.44</td>
</tr>
<tr>
<td>Structural facilitators</td>
<td>3.58</td>
<td>0.27</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Appointment adherence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structural barriers</td>
<td>4.46</td>
<td>1.84</td>
<td>1.32</td>
<td>0.25</td>
</tr>
<tr>
<td>Structural facilitators</td>
<td>5.90</td>
<td>0.09</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Research Question Four

Are maternal depression or other mental illness, proximity of HIV diagnosis, race, income, adolescence, high school education, poverty, substance abuse, pill burden, structural barriers to access, and structural facilitators to care significantly different as measured by the laboratory results, medication adherence, and appointment adherence of HIV-positive pregnant women, postpartum mothers, or their infants?

Logistic regression was used to address this hypothesis. The forward selection procedure was utilized to obtain the optimal model for each outcome variable. As shown in Table 4-8, the final analysis of Maximum Likelihood Estimates shows the following variables were significant to laboratory results: age ($p = 0.04$), maternal education ($p = 0.008$), membership in the baby group ($p = 0.0001$), or the dyad group ($p = 0.0001$). The association between positive laboratory results and young maternal age was inversely related, with an odds ratio of 0.6 (95% C.I. 0.40-0.98). Maternal education provided an odds ratio of 2.8 (95% C.I. 1.31-6.06). Comparing membership in the baby group or the dyad group to that of the postpartum mother group had an odds ratio of 31.7 (95% C.I.: 10.49-95.94). This means that young maternal age, maternal lack of a high school education or its equivalent, and simply being in the postpartum maternal group were most closely associated with poor laboratory findings. Babies were 31 times more likely to have therapeutic laboratory results than for those postpartum mothers or dyads.

Table 4-8. Summary of logistic regression analysis predicting favorable laboratory results

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald statistic</th>
<th>$p$</th>
<th>Odds ratio</th>
<th>95% Wald confidence limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.46</td>
<td>0.23</td>
<td>4.21</td>
<td>0.04</td>
<td>0.63</td>
<td>0.4-0.9</td>
</tr>
<tr>
<td>Education</td>
<td>1.04</td>
<td>0.39</td>
<td>7.03</td>
<td>0.008</td>
<td>2.80</td>
<td>1.3-6.1</td>
</tr>
<tr>
<td>Group: Baby</td>
<td>3.46</td>
<td>0.56</td>
<td>37.48</td>
<td>0.0001</td>
<td>31.72</td>
<td>10.49-95.94</td>
</tr>
<tr>
<td>Group: Dyad</td>
<td>3.46</td>
<td>0.56</td>
<td>37.48</td>
<td>0.0001</td>
<td>31.72</td>
<td>10.49-95.94</td>
</tr>
</tbody>
</table>
The final analysis of Maximum Likelihood Estimates shows the following variables (Table 4-9) were significant to medication adherence: maternal education (p = 0.005), being in the baby group (p = 0.0001), and being in the dyad group (p = 0.0001). The odds ratio estimates showed that mothers with a high school education or its equivalent had a 2.5 times greater chance (95% C. I.: 1.32-4.72) of adhering to their antiretroviral medications. Members of the baby group were almost 12 times more likely to receive their medications (95% C. I.: 5.29-25.39), and members of the dyad group were almost 15 times more likely to adhere to their medications (95% C. I. 6.4-34.58).

Table 4-9. Summary of logistic regression analysis predicting favorable medication adherence

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald statistic</th>
<th>p</th>
<th>Odds ratio</th>
<th>95% Wald confidence limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>0.91</td>
<td>0.33</td>
<td>7.85</td>
<td>0.0050</td>
<td>2.49</td>
<td>1.3-4.7</td>
</tr>
<tr>
<td>Group: Baby</td>
<td>2.45</td>
<td>0.4</td>
<td>37.5</td>
<td>0.0001</td>
<td>11.59</td>
<td>5.29-25.39</td>
</tr>
<tr>
<td>Group: Dyad</td>
<td>2.7</td>
<td>0.43</td>
<td>39.34</td>
<td>0.0001</td>
<td>14.87</td>
<td>6.4-34.6</td>
</tr>
</tbody>
</table>

Table 4-10 shows that the final analysis of Maximum Likelihood Estimates indicates the following variables were significant to adherence to the recommended clinic appointments: maternal age (p = 0.04), structural barriers (p = 0.0037) and membership in the dyad group (p = 0.0001). The odds ratio estimates (0.66) showed that younger age had a negative relationship to appointment adherence (95% C. I. 0.45-0.97), as did the presence of structural barriers odds ratio 0.32 (95% C. I. 0.15-0.69). The dyad group was 23 times more likely (95% C. I. 6.71-79.02) to have favorable appointment adherence.

Support for Hypothesis

Based on the results presented above, the hypothesis: Maternal depression or other mental illness, proximity of HIV diagnosis, race, income, adolescence, high school
education, substance abuse, pill burden, structural barriers to access, and structural facilitators to care are associated with a significant difference in adherence as measured by the laboratory results, missed medication doses, and delayed or missed clinic appointments of HIV-positive pregnant women, postpartum mothers, or their infants is supported and statistically significant.

Table 4-10. Summary of logistic regression analysis predicting favorable appointment adherence

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald statistic</th>
<th>p</th>
<th>Odds ratio</th>
<th>95% Wald confidence limits</th>
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<td>Age</td>
<td>-0.41</td>
<td>0.20</td>
<td>4.37</td>
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<td>0.4-0.9</td>
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<td>Education</td>
<td>-1.15</td>
<td>0.39</td>
<td>8.45</td>
<td>0.004</td>
<td>0.32</td>
<td>0.15-0.67</td>
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<tr>
<td>Group: Baby</td>
<td>0.62</td>
<td>0.41</td>
<td>2.28</td>
<td>0.13</td>
<td>1.86</td>
<td>0.83-4.15</td>
</tr>
<tr>
<td>Group: Dyad</td>
<td>3.14</td>
<td>0.63</td>
<td>24.85</td>
<td>0.0001</td>
<td>23.03</td>
<td>6.7-79</td>
</tr>
</tbody>
</table>
CHAPTER 5
DISCUSSION AND IMPLICATIONS

Purpose

The purpose of this study was to determine if previously identified barriers to HIV treatment adherence affect the perinatal dyad, the postpartum mother, or the exposed infant equally; and to determine if the proposed constructs of structural facilitators or structural barriers are associated with HIV treatment adherence in the perinatal dyad, the postpartum mother, or the exposed infant. The dependent variables were operationalized as follows: adherence to antiretroviral medication = self report of missing <10% of doses; adherence to appointment schedule = all primary and subspecialty care received within the recommended time frame; and therapeutic laboratory results = a stable or falling HIV viral load, and a stable or rising CD4 count.

The results showed that all outcome measures were significantly different between the infant and the postpartum mother groups. Further, exposure to the tested constructs of structural facilitators and structural barriers accounted for the majority of the differences. The use of the women and babies as their own comparisons (at different points in the care system) assured that the exposures to maternal factors were the same for all three groups. This allows more confidence that the differences expressed were likely associated with the exposures to structural barriers and structural facilitators.
Figure 5-1. Stigma theory in this study, as adapted from Goffman (1963)
Descriptive Statistics

Structural barriers were present for 69% of postpartum mothers, 31% of dyads, and 5% of babies. This shows heterogeneity between groups (p<.0001), with postpartum mothers significantly more likely to experience structural barriers to care than babies or dyads.

Structural facilitators also appeared heterogeneous between groups (p<.0001), being present for 100% of babies, 97% of dyads, and 6% of postpartum mothers. CD4 counts and HIV viral loads were significantly less likely (p<.0001) to be in the acceptable range for postpartum mothers (47%) than for babies (96%) or dyads (96%). Greater than 10% of medication doses were missed in 54% of postpartum mothers, while only 10% of babies and 8% of dyads reported missing >10% of doses. This shows a difference at the (p<.001) level of significance.

The last outcome that differed between groups was missed or delayed appointments. Again, postpartum mothers were less likely (p<.0001) to attend clinic appointments (48% missed) than were their babies (20% missed) or the same mothers during their pregnancy (3% missed).

Laboratory Results

Therapeutic laboratory results consisted of stable or decreasing viral loads and stable or increasing CD4 counts. For postpartum mothers, therapeutic laboratory results were positively impacted by maternal achievement of a high school diploma or equivalent (p=0.0286). In fact, even after adjusting for group membership, subjects in all groups were 2.24 times more likely to have positive laboratory findings if the mothers had a high school education or its equivalent.
Therapeutic laboratory results for postpartum mothers were negatively affected by prenatal maternal substance abuse at diagnosis according to the Fisher’s Exact Test (p=0.046). This effect is limited to the postpartum mothers, there was no general association (p=0.21). There were few subjects who were positive for illicit substances at the onset of their pregnancy (n=3), and those who were entered residential treatment programs to maintain custody of their babies. These residential programs required routine drug-testing, so ongoing use was not in question. Since there was not ongoing substance abuse, the clinical significance of this finding is not readily apparent.

Maternal CD4 counts and viral loads were also negatively affected by the presence of structural barriers to care (p=0.019). Again, no significant general association was found (p=0.11) to suggest these barriers affected the laboratory results of infants or dyads. This means that young maternal age, maternal lack of a high school education or its equivalent, and simply being in the postpartum maternal group were most closely associated with increased viral loads and decreased CD4 counts.

**Medication Adherence**

Medication adherence during pregnancy (group=dyad) was negatively affected by maternal mental illness according to the Fisher’s Exact Test (p=0.015), though maternal mental illness was not shown to have a general association once adjustment was made for group membership (p=0.84). Again, this was a relatively small group of women (n=21), and the clinical significance is not readily apparent.

Infant medication adherence was correlated with maternal education using the Fisher’s Exact Test (p=0.045). Postpartum maternal medication adherence was also positively correlated with maternal education (p=0.015). After adjusting for group
membership, a general association (p=0.005) existed. Subjects in all groups were 2.49 times more likely to report medication adherence if mothers had received a high school education or its equivalent.

Postpartum maternal medication adherence was negatively associated with prior maternal substance abuse according to analysis using the Fisher’s Exact Test (p=0.04). In fact, there was a general association (p=0.024) after adjustment for group membership. This means subjects in all groups were twice as likely to miss medications if the mother had a history of prior substance abuse.

Finally, there was a correlation between medication adherence and the presence of structural barriers noted (p=0.04) only for the postpartum mothers group. This means that only subjects in the postpartum mother group were likely to experience structural barriers that affected their medication adherence.

The logistic regression model showed that the best predictors of medication adherence were maternal education (p=.005), membership in the infant group (p<.0001), and membership in the dyad group (p<.0001). The odds ratio estimates show that postpartum mothers with a high school education or its equivalent have a 2.5 times greater chance of successful adherence to their antiretroviral medications. Simply being in the infant group meant subjects were almost 12 times more likely to receive their medications. Being in the dyad group meant subjects were almost 15 times more likely to adhere to their medications.

This shows that something about the infant and prenatal dyad groups significantly enhanced medication adherence. For postpartum mothers, the best predictor of therapeutic medication adherence was education.
Appointment Adherence

Postpartum maternal appointment adherence was negatively correlated with the presence of structural barriers ($p=0.03$). Statistical testing also showed a general association ($p=0.008$). In this case, the influence of structural barriers was so strong, that after adjusting for group membership subjects were about 3 times less likely to attend clinic appointments if there were structural barriers to doing so.

In contrast, postpartum maternal appointment adherence was positively affected by the presence of structural facilitators to care ($p=0.03$). There was also a general association after adjustment for group membership ($p=0.02$). Regardless of the group, subjects were 32 times more likely to adhere to the recommended clinic appointment schedule if structural facilitators were present.

The logistic regression model showed that older maternal age ($p=.0365$), presence of structural barriers ($p=.0037$) and membership in the dyad group ($p<0.0001$) best explained appointment adherence. The odds ratio estimates showed that young age had a negative relationship to appointment adherence (OR=0.66), as did the presence of structural barriers (OR=0.32). Membership in the dyad group increased the likelihood of adherence to appointments. In fact, women were 23 times more likely to attend clinic visits during the prenatal period than they were to continue their care after delivery.

Summary of Findings

Structural barriers were present for 69% of postpartum mothers, 31% of dyads, and 5% of infants ($p<.0001$). Structural facilitators were present for 100% of infants, 97% of dyads, and only 6% of mothers ($p<.0001$). This means that extrinsic structural barriers, including insurance limitations and complicated clinic admission procedures, were present for a majority of mothers and almost no infants. Conversely, extrinsic
structural facilitators, including comprehensive funding and streamlined clinic admission procedures were present for all of the infants and almost none of the mothers. This shows that policies favor infant outcomes by almost never presenting barriers to infant care, and almost always giving mothers the tools needed to succeed with the care of their infants. On the other hand, mothers were rarely the recipients of structural help for themselves, and experienced structural barriers over two-thirds of the time.

As for outcome measures, 96% of infants and dyads had acceptable laboratory results. This is in contrast to only 47% of postpartum mothers. This showed a significant difference (p<.0001). Medication adherence had a similar distribution, with only 10% of infants and 8% of dyads reporting poor adherence. Over half (54%) of postpartum mothers reported poor adherence, a significant difference again (p<.0001). Given these figures, the last outcome, adherence to recommended clinic appointments, is not surprising. Dyads were rarely nonadherent (3%), infants (20%), and postpartum mothers almost half of the time (48%). Postpartum mothers who had already demonstrated the ability to adhere to treatment during their pregnancies experienced the majority of nontherapeutic laboratory results, missed medications, and missed appointments.

**Missing and Excluded Data**

Complete data sets were obtained from 300 subjects. No data points were missing at the time of analysis due to availability of redundant charting via paper charts, computer programs, and across disciplines within the clinic.

The independent variable “pill burden” was operationalized to measure number and times of pills per day against the treatment norm or standard at the time of therapy. Because most subjects began medication therapy during their pregnancy (treatment
naïve), progression to burdensome regimens due to drug resistance was not found in any instance. Had this not been a chart review, self-reported pill burden as perceived by subjects would likely have been a valid dichotomous measure to add to the model. For purposes of this analysis, pill burden is shown as frequency only. It was not operationalized in this study in a manner that showed heterogeneity.

Maternal substance abuse is underrepresented in this sample because of the study purpose and its exclusion criteria. The purpose was to examine outcomes of mothers and babies when challenged with the same maternal environment. This prohibited analysis of babies that were not in maternal custody because the environment then differed from that of the mother. Mothers that utilized illicit drugs during pregnancy were likely to lose custody of their infants at least temporarily, and thus exclusion criteria eliminated these infants, their mothers, and the dyad from the sample.

**Ethical Considerations**

As previously stated, postpartum mothers who had already demonstrated the ability to adhere during their pregnancies experienced the majority of missed medications, missed appointments, and a resulting increase in their viral loads and decrease in their CD4 counts (immune function). With the exception of education, these results were not found to be associated with ways of describing these mothers, (i.e., black, poor, drug-addicted, or depressed). What did appear to influence outcomes was the structure of the health care system in which they were expected to function. The complexity of the system in fact, may be why an increase in maternal education was associated with successful treatment. For example, the mother of a neonate is given an actual physical supply of Retrovir for her baby and required to return-demonstrate proper administration by a HIV nurse specialist. The same nurse gives the mother an
appointment time and date for the infant to follow-up with the subspecialty nurse practitioner in the HIV clinic after discharge home.

The postpartum mother, on the other hand, has no mechanism in place to help her receive or continue her own medications, and is in fact, not allowed to make an appointment for subspecialty care until after her 6 week visit in the obstetrical clinic postpartum; a clinic that no longer addresses her HIV-related needs once she has delivered her baby. An additional requirement is that mothers “connect” with case management prior to entering care in the subspecialty clinic. Further, she likely loses access to medications in the interim, because the Medicaid that covered the pregnancy usually expires before (or if) she links with case management to begin the process to access the AIDS Drug Assistance Program (ADAP). It does appear that decisions made about who will receive what type of help through the maze of care is important to the overall health of HIV-positive women.

The people who decide what constitutes a scientific problem shape the world, because the world is shaped by research (Kane & Thomas, 2000). The development of knowledge is a political enterprise that reflects society’s current dominant values, including the determination of which groups and subjects should be researched and by whom (Browne, 2001). Since research is the foundation for best practice, it is important to include maternal outcome measures in treatment protocol. The results of this study suggest that a need for a more inclusive approach to maternal health in the perinatal and postnatal periods is justified by basic ethical concepts, including personhood and value of mothers and fetuses.

According to Beauchamp and Childress (1994), the first principle in bioethics is the respect for autonomy. This means persons who are able to make decisions about their
own care must be allowed to, and researchers and providers must respect these decisions. This does not happen when HIV-positive mothers are judged incapable of understanding risk and treatment options, or when treatment counseling consists of discussing fetal health in the absence of discussions of the impact of that treatment on maternal health. Anti-retroviral prophylaxis given to the fetus via the mother is not free from impact on the mother’s health. Viral mutation and resultant drug resistance are documented consequences of even short-term prophylaxis during the perinatal period (Toni et al., 2005).

Moreover, it is important to include maternal outcomes as a measure in any study that uses the bodies of mothers to impact the health of others. Successful adherence overall is predicated on patients understanding and accepting their diagnosis, and expression of a willingness to take medications (Rogers et al., 2001). Guidelines are evolving rapidly to allow delay in the introduction of antiretroviral medications until patients are ready. The aim is to minimize self and community harm by minimizing multiple drug resistant viral mutations and the waste of resources. Pregnant women are the exception to this rule, as the protection of the fetus is an immediate need, and waiting months or years for maternal readiness is not considered a viable option. Guidelines state that antiretroviral therapy must be started by week 14 of pregnancy, or as soon thereafter as the woman is identified as HIV-positive (Steinhart, Orrick, & Simpson, 2002). But ethicists caution not to overrule the decisions of mothers regarding their babies’ health, as the general view that being HIV-positive is the worst possible outcome for a baby may not be accurate when viewed in the full context of a mother’s world (Fu-Chang Tsai, 2001).
Reinforcement of the position that being HIV-positive is the worst possible thing that can happen devalues the lives of the mothers, whether or not that is the intention. Without a focus on the health outcomes of a baby and its mother, the message is reinforced at each encounter that the baby is the true patient.

One approach is to consider Clarke’s (1999) assertion that the mother and the fetus should be considered jointly as “the person” when making decisions about “the person’s” future. This appears to be the most sound answer to the question of which is of more value; to simply state that the question is void because they are the same individual. This is beneficial to the fetus, because the only relationship the fetus can form is one of biological dependence on the mother. The mother’s psychological and emotional dependence on the fetus is also honored. This position values the dyadic and interdependent nature of the mother and fetus, and as such, served as the ethical perspective of this research study.

The ethical position remains that to compromise either person would harm both. Since the mother and the fetus are both entitled to moral standing, there are duties owed to the dyad by the medical and research community. The absence of treatment for the millions of women infected with HIV while the prevention of mother to child transmission (MTCT) remains the focus of researchers and clinicians worldwide, uses the justification of the utilitarian argument that protecting exposed babies does the most good for the most people, with limited allocated resources. After all, the mothers are already infected. Alleviation of suffering in mothers is ignored in the name of cost-effectiveness. This is a contrived poverty because the resources exist to do both in the United States.

It is essential to remember that whether in the United States or elsewhere in the world, imbued in the value of the mother is the fact that she is a person with HIV. Harris
(1999) addressed the cost of acknowledging someone’s personhood—it brings her into the same moral category as those who are uninfected. Judging someone as a nonperson is a way of distancing her reality from everyone else’s. To acknowledge her sameness would be to admit that everyone is vulnerable to HIV-infection. This can be incredibly unsettling for the uninfected world. It is the duty of policy makers and providers to keep actual medical and research practice within the confines of moral behavior. This means that reinforcing the stigma placed on HIV-positive mothers through practices that excessively weight fetal outcome is both immoral and unethical.

**Significance**

Providers and policy makers focus on the cause most proximal to the symptom they are treating (Krieger, 1994). In the case of perinatal HIV transmission, the cause is exposure to the mother. But the more distal exposures that rendered the mother susceptible to infection go unchecked. Failure to address the larger disparities makes the prevention effort shortsighted. The same infants who benefited by the PACTG 076 protocol in the mid-1980s have now grown into impoverished, at-risk adolescents who engage in activities (other than exposure to their mothers) that could result in HIV infection. Children of minority groups whose contemporaries were spared by this protocol are now coming of age to bear their own exposed infants.

The value-laden term “mother-to-child transmission” (MTCT) is the acronym used by the scientific community worldwide to describe perinatal transmission. It assumes that the fetus is already born (child, not fetus, though the majority of transmissions do not occur after birth), and it assigns blame to the mother for giving the baby HIV. Though mothers often report primary risk for HIV infection to be unprotected
sex with the fathers of these babies, any assignment of responsibility to the father is absent.

Mother-to-child-transmission assumes the mother is exclusively to blame if her child is born with HIV. It makes her the executor of an immoral act upon a defenseless child, and justifies hostility toward her. Vertical transmission also denotes a direct route from mother to child. No value-neutral term exists (i.e., parent to child transmission). Since the trajectory of infection is more accurately father to child via mother, vertical transmission could more accurately be described as angular. This is supported by McNair and Prather’s (2004) recent findings indicating that a partner’s risk behaviors exert more influence on a woman’s HIV status than her own behavior. It follows that if a mother’s health is predicted by the behavior of the father, so then is the baby’s.

Interestingly, both the medical community and society place the sole responsibility and blame for the “high-risk” pregnancy on mothers. An example is the message conveyed in the High Risk Obstetrical Clinic (HROB) where the predominant message to HIV-positive mothers is one of saving the babies from the high-risk situations in which their mothers have placed them. In one qualitative study (Ingram & Hutchinson, 1999a), a black woman spoke of the hostility she felt every time she walked into the clinic to see a beautiful black baby on a state-sponsored prevention sign saying, “She has her daddy’s eyes and her mother’s AIDS” (Figure 5-2). She states, “When you are positive, you learn undertones.” These undertones, even in the healthcare community, may be a fundamental barrier to continued treatment for mothers after they have safely delivered their babies.
A mother whose social worth is reinforced by her ability to procreate must confront the knowledge that she will never have a nonpathological pregnancy. This distortion potentially impacts decisions about engagement in self-care, and encourages
further development of the already low expectations of the medical community. In effect, their fates in the biomedical equation are already cast.

Thus is created the new risk category for under-treated HIV- that of pregnant women. But it also creates the risk category of fetus of a minority mother, when again; the real risk category is sexual partner or offspring of a male who has sex with males. Providers speak candidly of the need to curtail reproductive activity in these mothers because of their presumptive treatment failure and the burden their orphaned or infected babies will place on society. The simple fact is, despite the increased number of pregnancies in which babies are exposed to HIV, less than 10 were reported as infected in Florida in 2004 (CDC, 2005).

Implications for Future Research

Existing literature does not reflect the real risk that without changing social and economic circumstances, these same HIV-negative babies and their friends would grow into adolescents and acquire their own HIV infections because the same social and economic challenges that plagued their mothers now place them at risk. Perinatal HIV literature has an overwhelming focus on the prevention of HIV-infection in the fetus/infant.

It can be argued that the real disease to be battled is hopelessness and a lack of agency—not just HIV infection. If this is so, then the public health establishment is not addressing the root problems, and will likely not make adequate gains in reducing HIV infections in minority populations. HIV-positive mothers seem in full recognition of the circumstances of their lives. Providers, however well intentioned, are unable to address what really needs to be changed to lower risk; namely the introduction of the hope for a
future and agency in individual lives. These barriers must be lifted through policy shifts at least at a community level. This is well out of the reach of individual providers.

In the literature, disparity within communities is frequently noted to affect health. It is not simply the absence of a wealth, but the also the presence of jealousy or envy of others’ wealth that affects health. Studies indicate that poor societies without income stratification have better health than wealthy societies with stratification (Farmer, 2003). In the most generous individual, existing beneath another’s level must create self-loathing. Farmer (2003) refers to the equalization of this disparity as creating “freedom from want.” It can be described as more than a freedom from want, but also the freedom from feeling less than others. In poor neighborhoods deprived of hope, and in the High Risk Obstetrical Clinic (HROB), deprived of joy that other mothers-to-be experience, this feeling of inadequacy is reinforced. The economy of want and despair thrive in the minority populations in the United States. Because social segregation is still the norm, minority people engage in most behaviors, including high-risk behaviors, with someone who is of the same minority, because that is who is closest and readily available.

Prevention efforts in Florida consist primarily of messages aimed at minority communities, a practice known as social marketing (Figure 5-3). People are encouraged to know their individual HIV status because knowledge is power. But without the power to decide when and with whom to engage in high-risk behaviors, and the social and structural support to seek treatment if infected, the expensive prevention message is pointless, because knowledge alone is nothing. Without the power to demand the honest disclosure of, and protection from infected partners, no prevention is likely to occur. What is needed is the power of minority females to demand to know the status of their partners, and once infected, to expect adequate medical treatment to extend their lives to
see their children grow. This begins with economic power and extends to social power, and is not adequately addressed by the prevalent message of “know your status.” A requirement for survival with HIV is the presence of enough social and economic capital to withstand the structural violence in place, including that in place in the health care system.

Figure 5-3. Florida Department of Health announcement, circa 2005

Research must begin with “why” infected individuals were disempowered even before they became infected, and what keeps them so now. These factors are what
Krieger (1994) refers to as the social and political determinants of health. Recent attention has been focused on the effects that groups, or memberships in groups, convey on the agency of individuals. When there is the lack of distinction between individuals and populations, and a tendency to view populations as the sum of the individuals that comprise them; the practice is termed biomedical individualism (Krieger 1994).

Any approach to understanding HIV-positive mothers and the decisions they make as individuals must be rooted in an understanding of the contextual elements of the communities that both support and constrain them. Health and behavior decisions made by these women regarding both themselves and their children must also be evaluated with this knowledge prior to labeling them unreachable or noncompliant. Effective interventions will not be derived and implemented without an understanding of the environment and constructs under which individuals operate. Often survival—not health—is the goal of these women; health decisions will always be subjugated by survival decisions. Understanding the context of decisions will help change environments that constrain individual agency.

**Suggestions for Further Research**

This study sought to determine if mothers and infants have different health outcomes during the perinatal and postnatal periods. It measured whether they experienced structural barriers and facilitators to care, and tried to determine if these or other exposures explained some of the differences in the outcomes they experienced. Certainly, this work has demonstrated that the health outcomes measured differ significantly between postpartum mothers and both groups containing their children (dyad and infant). It also indicates that postpartum mothers are much more likely to encounter barriers, and much less likely to encounter facilitators. The inverse is true for
dyads and infants—they are much more likely to experience facilitators and highly unlikely to encounter any barriers.

This research suggests that these findings are a natural result of assigning blame and stigma. An ethical orientation argues for inclusion of maternal health as an outcome measure in future studies. Left unanswered is the question of whether or not equal facilitation of maternal health care would in fact lead to improved maternal outcomes. However, this research suggests that HIV-positive mothers would go to any length to protect the health of their babies. Studies that introduce interventions to increase maternal role efficacy may show mothers the importance of surviving to see their children thrive.

Expansion of the current perinatal prevention protocol to include maternal health outcomes as measures of success may prompt more interventions. The creation of federal requirements to link infant and maternal outcomes at federally funded clinics would also improve maternal health at the clinic level. Educational efforts and surveys directed at provider attitudes may provide additional insight into discrimination at the clinic level. And importantly, qualitative studies are needed to describe how women experience the HIV treatment system, and to interpret how the messages given are heard. Further qualitative study of the role women feel they play in the lives of their babies would add tremendously to a mixed methods design that included an intervention to increase their role efficacy and to decrease their levels of depression.
APPENDIX A
DATA COLLECTION INSTRUMENT

DATA COLLECTION TOOL

ID# ________  Collector Initials ________  Date Collected ________

Q1 Maternal Age
14-16 years .........................................................
19-21 years .........................................................
22-24 years .........................................................
>24 years ...........................................................

Q2 Is there a history of maternal depression, cognitive impairment, or other mental illness?
Yes .................................................................
No .................................................................

Q3 Maternal Race
African American ..................................................
Caribbean Islander .............................................
Hispanic ...........................................................
Caucasian ..........................................................
Other ..............................................................

Q4 Was the initial diagnosis of HIV made during this pregnancy?
Yes .................................................................
No .................................................................

Q5 Was the household income below the poverty level at the time of delivery (see table)?
Yes .................................................................
No .................................................................

Q6 Did mother have a high school diploma/GED at the time of delivery?
Yes .................................................................
No .................................................................

Q7 Is there documented illicit drug or ETOH use during pregnancy or delivery?
Yes .................................................................
No .................................................................

Q8 Did the daily pill burden exceed the normative value for the time it was prescribed (see table)?
Yes .................................................................
No .................................................................

Q9 Were potential structural barriers to care present (see table)?
Yes .................................................................
No .................................................................

Q10 Were potential structural facilitators to care present (see table)?
Yes .................................................................
No .................................................................

Q11 Were lab values within expected guidelines (see table)?
Yes .................................................................
No .................................................................

Q12 Did subject miss less than 10% of prescribed doses of ART?
Yes .................................................................
No .................................................................

Q13 Were primary and HIV care obtained within one month of recommended schedule (see table)?
Yes .................................................................
No .................................................................
APPENDIX B
EXPECTED VALUES FOR DATA COLLECTION

Maternal Age at Time of Delivery
• 14 years to 18 years of age
• 19 years to 21 years of age
• 22 years to 24 years of age
• Over 24 years of age

Maternal Race
• African American
• Caribbean Islander
• Hispanic
• Caucasian
• Other

Pill Burden
• Infant—dose is four times daily for six weeks, then two times daily three days a week until six months of age or until instructed to stop
• Adult (1998-1999)—dose is 3 tabs three times a day and 1 tab two times a day
• Adult (2000-2004)—dose is five tabs twice a day

Structural Barriers
• Requirement to obtain own case manager prior to transfer of care from HROB to HUG Me clinic
• Requirement of additional intake process prior to transfer of care from HROB to HUG Me clinic
• Insurance coverage that prohibits mother or infant from receiving primary and specialty care at the same site

Structural Facilitators
• Automatic transfer of paperwork without intake appointment
• TOPWA or social work assistance to arrange transportation to appointments and to assist with financial paperwork
• ART medication dispensed instead of prescription given
• Nurse specialist and social worker assigned to attend clinic, follow progress and provide teaching

Lab Values
• Maternal HIV RNA PCR value (viral load) is stable or falling
• Maternal CD4 count (immune system) is stable or increasing
• Infant HIV DNA PCR remains negative
• Infant remains negative for PCP
Recommended Primary and Subspecialty Care Schedule

- Adult postpartum HIV clinic visits scheduled and maintained at least every 90 days
- Prenatal visits kept according to periodicity recommended in chart on prior visits
- Infant HIV testing and treatment visits performed within one month of recommended time
  - DNA PCR #1 performed by 4 weeks of age
  - DNA PCR #2 performed by 8 weeks of age
  - Bactrim obtained by 10 weeks of age
  - DNA PCR #3 performed by 5 months of age
  - EIA performed by 19 months of age

- Infant primary care performed within one month of recommended time, whether at HUG Me or other pediatric site
  - 2 month EPSDT performed by 3 months of age
  - 4 month EPSDT performed by 5 months of age
  - 6 month EPSDT performed by 7 months of age
  - 12 month EPSDT performed by 13 months of age
  - 18 month EPSDT performed by 19 months of age

Federal Poverty Guidelines

Year (one person, two person, three person, four person, each addt’l person)

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<td>2004</td>
<td>(9310, 12490, 15670, 18850, + 3180)</td>
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REFERENCES


BIOGRAPHICAL SKETCH

Patricia Stearnes Robinson graduated from the University of Central Florida with her Bachelor of Science in Nursing in 1994. She worked as a registered nurse with pediatric brain-injured patients until she moved to Gainesville to pursue her Master of Science in Nursing. While in Gainesville, she worked at Shands Hospital as a registered nurse with both pediatric oncology patients and, later, in the pediatric intensive care unit. She earned her Master of Science from the University of Florida in 2000. Since that time, she has worked as a pediatric nurse practitioner in an HIV clinic in Central Florida. She also taught both undergraduate and graduate nursing students at the University of Florida while earning her doctorate. Her minor course of study for her doctorate was epidemiology.