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Making a Choice: The Role of Education in Prenatal HIV Screening among Pregnant Women in Georgia

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An abstract of A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Science in Public Health in Health Policy and Health Services Research 2014

Abstract

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Over the past twenty years, prevalence of the human immunodeficiency virus (HIV) has grown substantially among women such that 25% of all HIV cases are now among women. This poses a unique challenge to childbearing women, as vertical transmission from mother to child during pregnancy is the primary mode of HIV transmission among children. Although current US guidelines recommend universal HIV screening during pregnancy using an opt-out testing program, so that all women are tested for HIV unless they explicitly refuse, a significant portion of pregnant women in the United States do not receive prenatal HIV testing. Yet few studies have examined demographic characteristics that may influence a mother's receipt of prenatal HIV testing. By analyzing a representative sample of women from Georgia who participated in the Pregnancy Risk Assessment Monitoring System (PRAMS) from 2004 to 2008, the objective of this project is to examine demographic predictors of HIV testing among pregnant women, focusing specifically on maternal education level. Based on an adaptation of Cheryl Cox's Interaction Model of Client Health Behavior, we analyzed the relationship between maternal education level and a mother's receipt of HIV testing via multinomial logistic regression. Eleven percent of the sample population did not receive a prenatal HIV test, and thirty-six percent of the sample did not report their HIV testing status. Regression results indicate that race, marital status, and primary source of insurance – not education level - are significant predictors of receipt of prenatal HIV testing. Additionally, white women may be more likely to refuse testing due to low self-perceived risk for HIV transmission. By understanding the relationship between maternal education level and a mother's decision on HIV testing during pregnancy, we may identify potential interventions to help achieve universal HIV screening in pregnant women.

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"Wear gratitude like a cloak and it will feed every corner of your life." - Rumi

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Introduction

Since its emergence in the 1980s, the human immunodeficiency virus (HIV) has affected the United States. Although early HIV incidence was focused in men who have sex with men (MSM), the populations at risk for HIV and the associated acquired immune deficiency syndrome (AIDS) have shifted. Over the past twenty years, HIV prevalence among women has grown substantially; the Centers for Disease Control and Prevention (CDC) reports that women account for twenty-five percent of all people living with HIV as of 2010 [1]. HIV/AIDS has become most widespread in the Southern region of the United States, and prevalence is higher among women in the South compared to other regions [2]. HIV infection poses a unique challenge to childbearing women, as vertical transmission from mother to child is the primary mode of HIV transmission among children [1, 3, 4]. However, if a woman discovers that she is HIV-positive during pregnancy and begins appropriate treatment, the risk of transmission to her child is less than 1% [4]. One of the key prevention strategies of mother-to-child transmission (MTCT) is prenatal HIV screening during pregnancy. Although key government players in the United States, including the CDC and the US Public Health Service, have pushed for universal HIV screening during pregnancy, a sizable portion of pregnant women in the US are not tested [5-7]. Approximately 15% of HIV-infected women in the US are unaware of their HIV status; thus, not receiving HIV screening during pregnancy puts women and their children at significant risk for MTCT [1]. Furthermore, demographic characteristics associated with socioeconomic status, particularly education, may influence a mother's risk of HIV infection [4, 8]. Therefore, it is crucial to understand the relationship between maternal demographics, such as education level, and a mother's receipt of prenatal HIV testing in order to identify interventions that may help us achieve universal HIV screening of pregnant women. The purpose of the current project is to examine demographic predictors of a mother's receipt of prenatal HIV testing, focusing on maternal education level.

HIV/AIDS in the United States

As of 2010, there are approximately 1.1 million people in the US living with HIV [8]. During the earliest years of the epidemic, HIV incidence was largely concentrated in men who have sex with men (MSM). However, infections in women, primarily through heterosexual transmission, quickly began to rise. Approximately 280,000 women, or one in four of all people living with HIV and one in five of new HIV infections, are living with HIV in the United States [1, 8]. Additionally, adult and adolescent females accounted for 25% of all AIDS diagnoses made during 2010 [9]. Across the country, the South is the region with the highest concentration of HIV and AIDS diagnoses [2, 9, 10], and approximately 48% of women living with HIV located in the South [8]. One of the particularly interesting trends in the HIV epidemic is the notion of geographically concentrated epidemics, or "hot spots," where high rates of HIV prevalence and incidence are found and associated with poverty and highly insular sexual networks [11, 12]. Over half of women living with HIV live in one of ten metropolitan areas, six of which are located in the South [8]. These areas include: Atlanta, GA (including the suburbs of Sandy Springs and Marietta); Baltimore, MD; Chicago, IL; Houston, TX; Los Angeles, CA; Miami, FL; New York, NY; Philadelphia, PA; San Juan, PR; and Washington, DC [13]. Although the identification of hot spots is useful for targeting the most vulnerable groups for HIV infection, the true prevalence and incidence of the disease is unknown. Out of the estimated 1.1 million people living with HIV in the US, one-fifth to one-quarter of HIV-positive persons are unaware of their HIV status [4, 14]. Recent evidence suggests that approximately 15% of women living with HIV are

unaware of their status [1]. From this perspective, the importance of HIV screening cannot be overstated.

HIV in Pregnant Women & Associated Issues

Untreated HIV-infection during pregnancy can pose serious risks for the mother and child. HIV transmission occurs via the transfer of one of four bodily fluids, blood, semen, vaginal fluid, or breast milk, from an HIV-infected individual to a non-infected individual [15]. Perinatal transmission, or the transmission of HIV from mother to child during pregnancy, labor and delivery, or breastfeeding (MTCT), is the number one cause of HIV acquisition among children under 13 years of age [3, 4]. In fact, as of 2009 almost 11,000 individuals living in the US had acquired HIV before the age of 13, with over 88% acquiring the disease via MTCT; additionally, over 90% of pediatric AIDS cases have been caused by perinatal MTCT [4, 6]. Early in the epidemic, an HIV-positive mother was unlikely to give birth to an uninfected child, and in 1991 over 1,600 cases of MTCT occurred in the United States [16]. Fortunately, advances in technology have allowed women with HIV to give birth to children with extremely low risk of transmission. In 1994, the National Institutes of Health (NIH) released ACTG 076, a study by the AIDS Clinical Trials Group (ACTG) showing that use of the antiretroviral drug zidovudine (AZT) during pregnancy and childbirth could reduce the risk of MTCT by up to two-thirds [8, 17]. Following ACTG 076, research has shown that receipt of antiretroviral therapy (ART) during pregnancy can reduce the risk of MTCT to 1-2% as well as improve maternal health outcomes [4, 18, 19]. These advanced treatment regimens for HIV-positive women have been tremendously successful; between 1992 and 2004, the United States has seen a 95% reduction in MTCT cases while the number of HIV-infected women giving birth has increased substantially [3, 8, 14, 20, 21].

Although the U.S. has made significant progress in the battle against MTCT, children continue to be born with perinatally acquired HIV. Estimates vary widely, as the true proportion of perinatal HIV infections includes infants born to undiagnosed mothers and infants who are removed from care before HIV diagnostic testing can be performed [22]. Regardless, current estimates suggest that 144 to 370 infants are born each year with HIV in the US [14, 23]. In addition to shouldering an extreme disease burden, perinatally infected children incur staggering healthcare expenditures: in 2001, the discounted lifetime treatment cost of a perinatal HIV patient was \$228,155 for 25 years [24]. Thus, it is in our best interest economically and socially to work to prevent MTCT. MTCT occurs primarily in HIV-infected women who lack prenatal care, which is critical when attempting to address MTCT; the earlier a diagnosis can be made, the more effective the treatment outcomes are for infants [11, 20, 25-27]. Standard prenatal care should provide multiple strategies for prevention of MTCT, including routine HIV screening, use of ART for treatment and prophylaxis for mother and child, Caesarian section, and avoidance of breastfeeding [28]. However, standard prenatal care is not always accessible. In a study of HIV-infected pregnant women, over 60% had missed at least one prevention strategy [28].

Perinatal prevention efforts have strengthened in the last five years. In 2009, the Joint United Nations Programme on HIV/AIDS (UNAIDS) called for the eradication of new pediatric HIV infections by 2015 [22]. Specifically, UNAIDS called for a 90% reduction of new pediatric HIV infections worldwide from 400,000 infections to less than

40,000 infections by 2015 [29]. In order to achieve this goal, challenges to prevention of MTCT must be addressed. One of the most serious challenges is the inconsistent provision of HIV screening during a woman's pregnancy. Lack of awareness of a mother's HIV status has been one of the most serious challenges to prevention of MTCT and the primary cause of new pediatric HIV infections [4, 30]. Although the CDC, PHS, and IOM (among others) strongly recommend universal prenatal HIV screening regardless of risk factors, 31% of mothers of HIV-infected infants did not receive an HIV test until after delivery, and Parra et al. (2001) found that up to 24% of pregnant women may not consent to prenatal HIV testing at all [6, 7, 31]. The CDC found that women are more likely to accept testing if their health care provider strongly recommends their use of testing [14].

Screening Policies and Regulations

Policies for HIV screening, particularly for pregnant women, have undergone many changes over time. In December 1985, the CDC released guidelines for "targeted testing" which recommended HIV counseling and testing for "at-risk" pregnant women and women who may become pregnant [8, 17]. "At-risk" pregnant women included women who had evidence of HIV infection (which was referred to as HTLV-III/LAV at the time), women who had injected drugs intravenously for nonmedical purposes, women who were born in countries where heterosexual transmission was thought to play a major role, women who had engaged in prostitution, or women who were or had been sex partners of intravenous (IV) drug abusers, bisexual men, hemophilic men, men with HTLV-III/LAV infection or men born in countries where heterosexual transmission was thought to play a major role [32]. Women who were not considered "at-risk" were not recommended to receive HIV counseling and testing [8]. Under this approach, many HIV-infected pregnant women were not screened due to inaccurate perceptions of risk, both on behalf of the patient and of the provider [17]. Following the release of ACTG 076, in July 1995, the PHS released updated HIV counseling and testing guidelines, which suggested replacing targeted HIV testing with a policy of universal testing for pregnant women [17]. Under both targeted testing and universal testing methodologies, providers utilized an "opt-in" testing approach. With the opt-in approach, pregnant women were given pre-test HIV counseling, asked if they would like to receive an HIV test and, if so, provided written consent [7, 33]. In 2006, the CDC released updated HIV testing guidelines that called for universal testing for *all* people in the United States aged 13-64 [14]. These new guidelines reemphasized routine HIV screening in all pregnant women, recommending an "opt-out" approach for screening [14]. In the opt-out approach, pregnant women are informed than an HIV test will be included in routine prenatal blood work and that they may decline. Unless they decline, an HIV test will be performed [7]. The CDC emphasized the opt-out strategy for a number of reasons: by 2006, treatment with highly-active ART (HAART) was widely available and more effective when started earlier in the course of HIV infection; research showed that individuals who are aware of their sero-status are less likely to transmit the disease; the advancement of HIV testing technology (including rapid HIV tests) allowed for testing to become more accessible, expanding the venues in which it could be implemented; and evidence indicated that opt-in programs had significantly lower rates of screening than did opt-out programs (25%-83% vs. 85%-98%, respectively) [10, 33]. Although the CDC released these recommendations for broad implementation, individual states and

providers have not necessarily universally adopted them. Fortunately, financial access to testing is not a barrier, as insurance providers usually cover the costs of HIV screening; under most circumstances, private and public health care providers, including Medicaid, cover the costs of prenatal HIV tests and for those who are uninsured, free testing is usually available [31].

In the state of Georgia, a pregnant woman must be tested for HIV at some point during gestation and at delivery by the physician or health care provider who assumes responsibility for her prenatal care, unless the women refuses [34]. If, at the time of delivery, a woman's HIV status is undocumented, the physician or health care provider in attendance shall order an HIV test, unless the woman specifically refuses [34]. In all circumstances, HIV screening is performed using an opt-out approach, and women may decline testing [34]. Additionally, the state Medicaid program and most private insurers provide coverage of prenatal HIV screening, including it as part of routine prenatal care [35].

HIV Screening

HIV screening is the first step in HIV prevention. Screening rates vary widely in different populations [36]. While in the early stages of the epidemic HIV testing rates among women were low, over time women have developed higher screening rates than men due in part to the numerous policies recommending HIV testing during pregnancy [36, 37]. Among women in the United States aged 18-64, 57% have reported being tested for HIV at some point in time. However, only 20% of this same population reported being tested being tested within the last year [8]. Women who do not become pregnant are less likely to receive testing: an analysis of responses from the 2001-2002 BRFSS showed that,

among women aged 18-44, 54% of pregnant women reported testing within the last year, compared to 15% of non-pregnant women [38]. Similarly, non-pregnant women were more likely to report never having been tested compared to pregnant women (40% vs. 18%, respectively) [38]. While pregnant women are more likely to receive an HIV test than non-pregnant women, universal screening is not being achieved.

Although the public health benefits of prenatal HIV screening are clear, HIV test acceptance rates during pregnancy vary widely, from 36% to 98%, depending on the population [3]. Furthermore, some studies have found that up to 22% of pregnant women do not consent to prenatal HIV testing in the United States [23]. An assessment conducted by Dr. John Anderson and his colleagues that surveyed providers in four geographic areas – North Carolina, Connecticut, Brooklyn, New York and Florida – found that 95%-99% of providers routinely offered HIV testing to all pregnant women in their care [39]. Acceptance rates ranged from 64%-89%, and the number of providers reporting that all of their patients had been tested ranged from 12%-62% [39]. An analysis of data from the 2002 National Survey of Family Growth found that, of all women who completed a pregnancy in the 12 months prior to the interview, only 69% reported receiving a prenatal HIV test [31]. Similarly, a 2008 study of 653 HIV-negative, recently-pregnant women across the nation found that 32% of women were not offered an HIV test during their pregnancy, and 6% declined testing [40]. In order to address this issue and work towards universal testing, it is crucial that we understand the extent to which women are receiving testing during pregnancy and the characteristics of those who are not [38].

Testing Barriers

Several barriers to prenatal HIV testing have been identified. Patient-level barriers include late entry into prenatal care, misperceptions of personal HIV risk, not being offered an HIV test during prenatal care, stigma associated with HIV, and fears about discrimination, judgments, and the negative effect of a positive diagnosis on personal relationships [14, 23, 39, 41, 42]. However, by and large, patients generally accept HIV testing [43]. Reasons for refusing an HIV test include: administrative and scheduling difficulties, previous testing, lack of endorsement of testing by provider, not wanting to know HIV status, not being sure if previous testing had been done, wanting to wait until the baby was born, not being able to afford the test, fear of being stigmatized, denial of risk, fatalism about life, fear of rejection, or because they simply do not believe themselves to be at risk [3, 6, 14, 23, 39, 42, 44]. However, women are more likely to accept HIV testing when they perceive their own HIV risk to be elevated, providers recommend testing as a fundamental part of appropriate medical care, and both clients and providers understand that testing is beneficial for early diagnosis and ultimately, the health of the client and her baby [23, 45]. Provider-level barriers include provider misperceptions of patient's risk, insufficient time, lack of knowledge/training, fear of offending the patient, concern about informing an HIV-positive patient, lack of resources, and inadequate reimbursement [5, 10, 14, 43]. Finally, system-level barriers include state and other federal agency laws that conflict with CDC recommendations, such as utilizing an opt-in approach [10, 14]. Many of these provider- and systems-level barriers are issues are difficult to address, but interventions may alleviate some of the patient-level barriers. For example, an individual's self-perceived risk versus their actual risk is often wildly

different, creating one of the most significant patient-level barriers to HIV screening. A study of heterosexual individuals visiting a sexually transmitted infection (STI) clinic in Chicago found that, of 359 individuals categorized as high-risk for HIV infection, 84% perceived themselves to be no- or low-risk [46]. Providing risk-reduction education for HIV may allow individuals to more accurately assess their own risk and to better understand the importance of universal HIV screening, particularly during pregnancy.

The Role of Demographics and Education

Demographic characteristics associated with health behaviors often demonstrate larger trends that occur in healthcare. Generally, demographic factors such as race/ethnicity, insurance type, marital status, and education level influence an individual's risk for HIV infection [4]. Although women living with HIV are a generally diverse group, numerous studies examining the demographic characteristics of HIVinfected women have discovered that women living with HIV are more likely to be black, single or in a relationship but not cohabitating, and insured with a high school degree/GED or some college [47-51].

Education level, along with limited access to high-quality health care and housing, are socioeconomic issues associated with poverty that directly and/or indirectly increases the risk factors for HIV infection [4]. From 1993 to 2007, a majority of deaths due to HIV within races/ethnicities occurred among individuals with fewer than 12 years of educational attainment [52]. When considering HIV-positive women, individuals who did not graduate from high school were more likely to be HIV-positive than those with a high school education [8]. Maternal education has also been linked to infant mortality; in both developed and developing countries, mother's education has been linked to lower infant mortality rates, partially because more highly educated women are more likely to pursue health-enhancing activities and medical care [53]. Maternal education may translate to a woman's knowledge about HIV prevention and transmission, which would influence her decision to accept or decline an HIV test.

Knowledge of HIV prevention and transmission is particularly low in the United States. Just over one half of US women of childbearing age had the correct knowledge of effective prevention strategies against perinatal HIV transmission [45]. Interestingly, Dr. Anderson and his colleagues discovered that knowledge about treatment to prevent MTCT was associated with having a college level education [45]. Additionally, education level may influence an individual's assessment of the importance of an HIV test. Kelly and Harrison (2008) discovered that almost all women with no education beyond high school reported that their HIV screen was presented as being very important, compared to only 54% of college graduates [17]. That importance does not necessarily translate into knowledge of adherence to HIV screening guidelines; only 39% of women with less than a high school education were aware that HIV screening is required during pregnancy [17].

Overall, the relationship between education level and prenatal HIV testing rates is unclear. A number of studies have found that individuals with higher education levels are more likely to be tested; for example, Ginger Gossman et al. (2008) found that women with lower education levels were less likely to be tested with HIV [54]. Additional research has shown that individuals who refuse testing are more likely to have a higher education level; Liddicoat et al. reported that patients with more than a high school education were more likely to refuse HIV testing [36, 37, 41, 44, 55, 56]. Yet, other studies have found that individuals' education levels are not significantly related to their likelihood to get an HIV test [57, 58]. In short, there is little consensus on the relationship between education level and acceptance rates of HIV testing, and little of this literature is focused on pregnant women.

While existing literature provides insight into the role of education among prenatal health behaviors and health education, few studies have explored the specific demographic characteristics of women who decline HIV testing during pregnancy. Among those who have, only a handful have included maternal education as a demographic variable of interest, and none have focused on the specific relationship of maternal education to a woman's likelihood to accept or decline an HIV test. Additionally, many of the studies focused on international populations, mostly in developing countries, and, therefore, limited the generalizability of results and the ability to explain trends among pregnant women in the United States [3, 41, 53, 54].

Interactive Model of Client Health Behavior

In order to address the role of education in receipt of HIV screening, we adapted Cheryl Cox's Interactive Model of Client Health Behavior (IMCHB), a client-focused theoretical framework that has been used to explain patient health behavior [59]. Cox noted numerous weaknesses in regards to client health behavior: ideological slants limited the approachability of theoretical frameworks outside of their discipline; many existing frameworks tended to approach disease as solely a biological, rather than a social or environmental, entity; and few models addressed the role of healthcare professionals in effecting client decision making [59]. She, therefore, Cox designed the IMCHB to: 1) identify factors that define a client's physical and psychosocioenvironmental individuality; 2) identify elements of provider interactions that potentially have an impact on client health outcomes; and 3) demonstrate the interrelationships between client and provider factors and their collective impact on client health outcomes [59, 60]. The overall model is abstract, designed not to represent reality, but to provide clinicians and researchers with the concepts that should be operationalized and transformed to represent a specific health care issue [60]. The three main domains of the model are client singularity, client-provider interaction, and client health outcomes [59, 60]. Primary emphasis is placed on the *process* by which the singularity of each individual client, in combination with client-provider interaction, influences health care behavior [59]. In this model, clients are assumed to be capable of making informed, competent choices about their health care behavior; aspects of client singularity and the client-provider relationship influence these choices [59]. For the purposes of this research project, we adapted the IMCHB to focus on the health care issue of interest: a mother's receipt of prenatal HIV testing, as is further detailed in the following chapter.

Summary

While the 30th anniversary of the HIV epidemic has come and gone, the disease continues to affect individual and community health, both domestically and abroad. In order to clarify the relationship between demographics and acceptance of HIV testing, this research project will explore on a large scale the relationship between maternal education level and a woman's decision whether or not to get an HIV test during her pregnancy. Using data from Phase 5 (2004-2008) of the CDC's Pregnancy Risk Assessment Monitoring System (PRAMS), we will analyze responses from women in Georgia to determine whether does maternal education level predict whether a woman

receives an HIV test during her pregnancy and whether maternal education level predict a woman's reason for opting out of HIV screening during her pregnancy. By addressing these two questions using a personalized adaptation of the IMCHB, we hope to fill in the gaps of information relating maternal education level to a woman's decision on whether or not she receives an HIV test during her pregnancy.

Methodology

Research Questions

This study will explore the relationship between maternal education level and receipt of prenatal HIV testing (1) and explore the relationship between maternal education level and a woman's reason for refusing an HIV test (2).

Primary research question (1) – Does maternal education level predict whether a pregnant woman receives an HIV test during her pregnancy?

H₁: Mothers with higher education levels are less likely to receive an HIV test during pregnancy.

Sub-question (2) – Does maternal education level predict a woman's reason for opting out of HIV testing during her pregnancy?

 H_{2a} : Mothers with higher education levels are more likely to opt out due to the assumption that they are not at risk for HIV transmission.

 H_{2b} : Mothers with lower education levels are more likely to opt out because they are afraid to know their HIV status.

Data Source

The data source for this study is the CDC's Pregnancy Risk Assessment Monitoring System (PRAMS), a national representative survey of women who have had a recent live birth. Each state involved in the PRAMS data collection draws a stratified systematic sample of 100 to 150 new mothers every month from eligible birth certificates, totaling anywhere from 1,000 to 3,400 women annually. Typically women from high-risk backgrounds are sampled at a higher rate; most states, including Georgia, oversample for low birth weight and stratify by birth weight and mother's race or ethnicity [61]. Survey responses from mothers are then linked to extracted birth certificate information for analysis. Detailed information on the PRAMS methodological protocol can be found on the PRAMS website [61].

For the purposes of this analysis, Phase 5 PRAMS data was obtained from the Georgia Department of Public Health (GDPH). This data included a representative stratified systematic sample of women in Georgia who had a live birth between 2004 and 2008. Although the initial sample was comprised of approximately 11,000 women (N = 10,752), some observations were excluded if they were missing key information. Mothers whose education level, race, age, marital status, and tobacco use during pregnancy was missing were excluded (N = 734). No other exclusion criteria were employed, bringing the total sample down to 10,018 women.

PRAMS datasets are not publicly available. This data was provided to the study team by the GDPH's PRAMS epidemiologist upon completion of a data request by the Principal Investigator. This study's protocol was reviewed by the Emory Institutional Review Board, #IRB00067901, and granted exempt approval on 7/25/2013.

Conceptual Framework

As discussed previously, the conceptual framework employed by this study is an adapted version of Chervl Cox's Interaction Model of Client Health Behavior (IMCHB), seen in Figure 1 [59]. The first element of the model, client singularity, includes two elements: background variables and dynamic variables. Background variables include characteristics about an individual patient, such as demographic characteristics, social influences, previous health care experiences and environmental resources. In contrast, dynamic variables cannot necessarily be easily measured and quantified, including items such as intrinsic motivation, affective response and cognitive appraisal. The background variables interact with one another and help determine the dynamic variables of a patient, most of which cannot be explicitly quantified (shown in dashed boxes in Figure 1). Elements of client singularity then feed into the next domain of the framework: clientprovider interaction. The client-provider interaction domain is defined by four elements: affective support, health information, decisional control and professional/technical competencies. Finally, client singularity and the client-provider interaction determine the final domain of the framework: client health outcomes. Client health outcomes in our context are measured in terms of utilization of health care services (i.e. prenatal HIV test). One of our additions to Cox's original model is a "health systems processes" domain, which captures elements of the external healthcare environment, such as local, state and federal healthcare legislation. Although not explicitly shown, important to note is that variables within each domain interact with one another. Additionally, the dashed boxes surrounding "social influence," "dynamic variables" and "client-provider

interactions" signify that these variables are not explicitly measured within the PRAMS dataset.

In the context of this project, the primary client singularity characteristic of interest is the independent variable, maternal education level, which is marked by a blue box. Education level, like other background variables, influences many of the dynamic variables of the patient, and together these patient singularities affect the outcome of client-provider interactions. However, the client-provider domain is the least emphasized in the context of this study due to its unobservable nature in our data. Education level, dynamic client singularities and client-provider interactions all influence the primary health outcome of interest: utilization of prenatal HIV testing. Utilization of prenatal HIV testing is the dependent variable of interest, and is marked by a green box. The red arrow in Figure 1 indicates the relationship of interest, that between maternal education level and utilization of prenatal HIV testing. Finally, the most important health systems process for this context, the 2006 prenatal HIV screening policy change to an opt-out system, influences client-provider interactions and health outcomes.

17

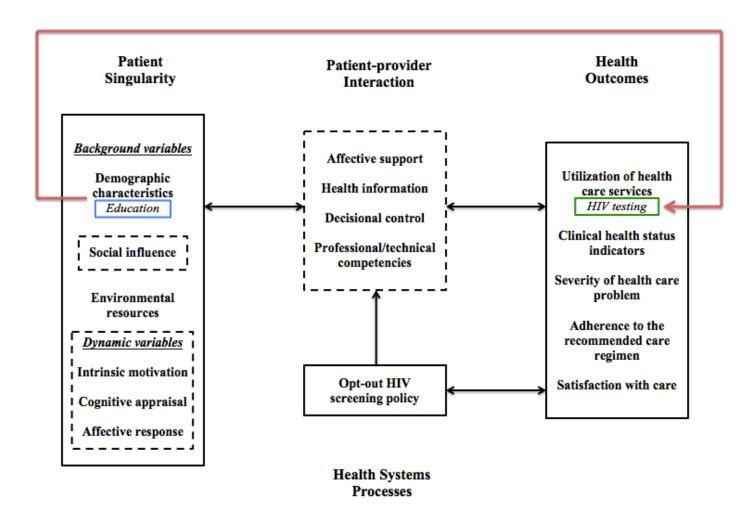


Figure 1. Conceptual framework, adapted from IMCHB (Cox, 1982)

Dependent Variable

The primary dependent variable used in this study is a mother's response to the question, "at any time during your most recent pregnancy or delivery, did you have a test for HIV (the virus that causes AIDS)?" For the purposes of statistical analysis, responses were coded into a multinomial (0/1/2) outcome variable. A 0 indicates that a mother responded in the affirmative (i.e. "Yes, I did receive a test"), a 1 indicates that a mother responded in the negative (i.e. "No, I did not receive a test"), and a 2 indicates that a mother wariable was used as the dependent variable for the primary research question of this study, which was analyzed using the full sample of 10,018 women.

Women who did not receive an HIV test were then asked if they were offered an HIV test during their pregnancy. If they were offered a test, they were then asked if they turned down the HIV test. For those indicating that they refused a test, the secondary dependent variable used in this study is a mother's multinomial response to the question, "why did you turn down the HIV test?" Possible answers to this question included: 1) "I did not think I was at risk for HIV;" 2) "I did not want people to think I was at risk for HIV;" 3) "I was afraid of getting the result;" 4) "I was tested before this pregnancy, and did not think I needed to be tested again;" or 5) "Other, please tell us." Because women were not limited to one answer choice, running a multinomial logistic regression was not an option. Instead, a binary 0/1 variable was created for each of these answer choices, and separate binary logistic regression was performed on each of these binary variables. Out of the 10,018 women included in the original sample, only 325 indicated that they refused a prenatal HIV test. Further, not all women who reported refusing provided a reason for

refusal. Thus, the sample size for this sub-question was much smaller than that of the primary research question, making the results less generalizable.

Independent Variable

The independent variable of interest for both research questions was maternal education level. Extracted from the mother's birth certificate, maternal education level was reported as one of the following ranges of years in which the mother was in school: 1) 0-8 years; 2) 9-11 years; 3) 12 years; 4) 13-15 years; or 5) 16+ years. To improve the ease of data interpretation, these responses were transformed into a categorical variable containing the following categories: some high school or below (0-8 years and 9-11 years combined), high school graduate (12 years), some college (13-15 years), or college graduate (16+ years). This variable was the main independent variable for the primary research question as well as the research sub-question.

Covariates

Race [Categorical] – This variable indicates a mother's racial self-identification. Due to a vast majority of the unweighted sample identifying as either black (51%) or white (43%), maternal race was categorized into one of three groups: Black, White, or Other. "Other" includes those who self-identify as American Indian, Chinese, Japanese, Filipino, Hawaiian, other non-white, Alaska Native, other Asian, or mixed race.

Age [Continuous] – Age is measured continuously in PRAMS, ranging from 13 years (youngest participant) to 50 years (oldest participant) in this sample.

Married [Binary] – This binary variable indicates whether a woman was married or not married. A mother's marital status may influence her general health behaviors and the

timeliness of her prenatal care. Literature has shown that married individuals are healthier, practice better health behaviors and are more likely to use health care, compared to single individuals [62].

Prenatal care [Categorical] – This variable indicates whether a woman received timely prenatal care. According to the U.S. Department of Health and Human Service's Health Resources and Services Administration, receipt of prenatal care during the first trimester (months 1-3 or weeks 1-12) is a reflection of a timely receipt of prenatal care [63]. A well-accepted strategy to improve maternal and child health outcomes, timely prenatal care improves birth weight and decreases a mother's risk of preterm delivery [63]. Additionally, infants born to mothers receiving no prenatal care have a mortality rate five times higher than infants born to mothers who received prenatal care in the first trimester [63]. Receiving timely prenatal care may speak to a woman's general health behaviors, and thus a binary variable was created to assess whether a woman attended her first prenatal visit before or after the beginning of her second trimester (i.e. month 4 or week 13). Prenatal care was categorized into one of three groups: timely prenatal care (i.e. "Yes"), if a woman attended her first prenatal care visit before the beginning of her second trimester; untimely prenatal care (i.e. "No"), if a woman did not attend her first prenatal care visit until after her second trimester began; or unknown timing of prenatal care (i.e. "Unknown"), if a woman did not report information on her first prenatal care visit.

Tobacco use during pregnancy [Binary] – This binary variable was included in order to provide insight into a mother's health behaviors. If a woman reported smoking during

pregnancy, this participation in high-risk health behaviors may influence both her awareness about the importance of prenatal HIV testing and her decision to receive an HIV test. Thus, this variable essentially operates as a proxy for good health behaviors.

Insurance [Categorical] - This variable examines a mother's primary source of insurance at labor and delivery. Because HIV testing can be expensive, uninsured mothers or mothers who are unaware of their provider's coverage of HIV testing may be less likely to accept a testing because they do not want to incur the out-of-pocket cost of the test. In fact, two women in the sample reported refusing a prenatal HIV test because the out-ofpocket cost was too high (see Results chapter). Thus, it is important to know a mother's primary source of insurance. This was determined by creating a categorical insurance status variable based on the party that paid for the delivery. Mothers indicating that insurance/HMO or Military paid for the delivery were considered privately insured (i.e. "Private"). Mothers indicating that Medicaid paid for the delivery were considered insured under Medicaid (i.e. "Medicaid"). Mothers indicating that another source paid for the delivery were considered insured by "Other". Mothers indicating that her delivery was paid for by her income or that she still owes for her delivery were considered uninsured (i.e. "Uninsured"). Finally, mothers who did not provide information on how their delivery was paid for were considered to have an unknown primary source of insurance (i.e. "Unknown").

*Age*education* [Interaction] – Because there are mothers in the sample that may not have completed their schooling yet, their education may be considered unfinished even if they are continuing to pursue education. Maternal education level may have an effect on the

outcome of interest depending on the age (and thus education level) of the mother. Due to this confounding between age and maternal education level, we created an interaction term between age and maternal education level to correct this bias.

Statistical Analysis

In order to address these questions, we undertook three analyses. First, we conducted descriptive analyses on the sample to determine the distribution of education level, age, race, income level, marital status, prenatal care receipt, smoking status, and insurance type within the sample. Additionally, we calculated the proportion of women who received a prenatal HIV test in the sample and, among women who refused testing, the frequency of their various responses to the question "why did you turn down the HIV test?" For women who chose the "Other, please specify" option, we briefly explored their qualitative responses.

Second, we performed a multinomial logistic regression on the sample in order to answer the primary research question exploring the relationship between maternal education level and a mother's receipt of a prenatal HIV test. Using the following model, we regressed the multichotomous HIV testing variable against education level and the numerous covariates described above, reporting conditional means, marginal effects and corresponding p-values for each outcome (i.e. "Yes," "No," or "Unknown") at a significance level of p=0.05. The base outcome group was "Yes," the reference group for the education variable was "some high school or less," the reference group for the race variable was "black," the reference group for the timeliness of prenatal care was "no," and the reference group for insurance type was "Medicaid."

$$\begin{split} \text{HIV Test} &= \beta_{0} + \beta_{1} * \text{High school graduate} + \beta_{2} * \text{Some college} + \beta_{3} \\ & * \text{College graduate} + \beta_{4} * \text{Maternal age} + \beta_{5} * \text{Other} + \beta_{6} * \text{White} \\ & + \beta_{7} * \text{Married} + \beta_{8} * \text{Tobacco} + \beta_{9} * \text{Private} + \beta_{10} * \text{Other} + \beta_{11} \\ & * \text{Uninsured} + \beta_{12} * \text{Unknown} + \beta_{13} * \text{Untimely PNC} + \beta_{14} \\ & * \text{Unknown PNC} + \beta_{15} * (age * education) + \varepsilon \end{split}$$

Third, we performed a series of binary logistic regressions on the sample of women who refused prenatal HIV testing in order to answer the research sub-question about the relationship between maternal education level and a mother's reason for opting out of a prenatal HIV test. Using the following model, we separately regressed the five dichotomous reason-for-refusal variables against education level and the numerous covariates described above at a significance level of p=0.10. We utilized the same reference groups for the independent variable and the covariates described in the multinomial regression above, reporting odds ratios and corresponding p-values for this regression [64, 65].

 $= \beta_{0} + \beta_{1} * High school graduate + \beta_{2} * Some college + \beta_{3}$ $* College graduate + \beta_{4} * Maternal age + \beta_{5} * Other + \beta_{6} * White$ $+ \beta_{7} * Married + \beta_{8} * Tobacco + \beta_{9} * Private + \beta_{10} * Other + \beta_{11}$ $* Uninsured + \beta_{12} * Unknown + \beta_{13} * Untimely PNC + \beta_{14}$ $* Unknown PNC + \beta_{15} * (age * education) + \varepsilon$

Finally, we explored the responses of women who selected the "Other, please tell us" answer choice to the question, "why did you turn down the HIV test?" Fifteen out of twenty women who selected the "Other" category provided written answers to this question. Answers are presented in Table 4 as they were written by each respondent (e.g. "I am not at all at risk") or grouped by theme (e.g. women indicating that they already knew they were HIV-negative were grouped into the category, "Knows they are HIV-negative").

Data cleaning and formatting was performed in SAS version 9.3 of the SAS Institute (SAS Institute, 2008). Data manipulation and analysis was performed in Stata 13.0, controlling for the complex survey design of the dataset (StataCorp, 2013).

Results

Descriptive Statistics – Overall Sample

The weighted descriptive statistics of the overall sample (n=10,018) and the three groups of interest are presented in Tables 1 and 2, respectively. Among the overall sample, the largest proportion of mothers had a high school education (33%), followed by a college education (24%). The majority of the sample was white (59%) and one-third of the population was black (32%). Interestingly, a majority of mothers were on the opposite ends of the income spectrum: the largest proportion of women made \$50,000 or more during the 12 months prior to this pregnancy (32%), while the next largest proportion of women made less than \$10,000 in that same 12 months (24%). Over 58% of the sample was married, 85% received timely prenatal care and 5% of the sample smoked during their pregnancy. At delivery, a majority of women were insured via Medicaid (51%) or private insurance (45%).

Seen in the first column of Table 2, the demographic trends among the group of mothers who received a prenatal HIV test were similar to the overall sample: the highest

proportion of women had a high school education (33%), were white (54%), made \$50,000 or more (29%), were married (53%), received timely prenatal care (85%), were insured via Medicaid (56%) or private insurance (42%), and 6% of the sample smoked. The group of mothers with unknown HIV testing status, seen in the third column of Table 2, were less educated, less wealthy, and more likely to be white: 63% of the sample had either some high school or below or were high school graduates, 67% of the sample was white, 24% made \$50,000 or more, fewer women received timely prenatal care (80%), and almost identical proportions of women were insured via Medicaid (52%) or private insurance (40%). However, a higher proportion of the sample was uninsured at delivery (5%). Demographic trends varied further among mothers who did not receive a prenatal HIV test, seen in the second column of Table 2. These women were more highly educated, with the largest proportion of women having graduated from college (35%), and were much more likely to be white (76%), make \$50,000 or more (44%), be married (73%), have private insurance (61%) and less likely to smoke (3%). All demographic variations between these three groups were statistically significant at p < 0.01.

| Factor | Overall N=10,018 [(%) or mean (SD)] | |
|--------------------------|---|--|
| Education Level | | |
| Some high school or less | 20.5 | |
| High school graduate | 32.6 | |
| Some college | 22.6 | |
| College graduate | 24.2 | |
| Race | | |
| Black | 32.0 | |
| Other | 8.7 | |
| White | 59.3 | |
| Income° | | |
| Less than \$10,000 | 24.3 | |
| \$10,000 to \$14,999 | 9.9 | |
| \$15,000 to \$19,999 | 6.6 | |
| \$20,000 to \$24,999 | 9.0 | |
| \$25,000 to \$34,999 | 10.7 | |
| \$35,000 to \$49,999 | 8.0 | |
| \$50,000 or more | 31.6 | |
| Age | 26.4 (6.3) | |
| Marital Status | | |
| Married | 57.9 | |
| Timely PNC | | |
| Yes | 84.4 | |
| No | 11.1 | |
| Unknown | 4.5 | |
| Smoker | | |
| Yes | 5.3 | |
| Insured | | |
| Private | 45.2 | |
| Medicaid | 51.3 | |
| Other | 0.4 | |
| Uninsured | 2.1 | |
| Unknown | 1.0 | |

 Table 1. Weighted Descriptive Statistics for Overall Sample (%)

° 40% of sample missing; N=5,670

| Factor | HIV test: Yes N=5,101 [(%) or mean (SD)] | HIV test: No N=1,087 | HIV test: Unknown N=3,830 |
|--------------------------|--|-------------------------|---------------------------------|
| Education Level* | | | |
| Some high school or less | 20.9 | 24.4 | 29.3 |
| High school graduate | 33.3 | 29.6 | 33.5 |
| Some college | 22.6 | 20.9 | 19.8 |
| College graduate | 22.4 | 35.0 | 17.4 |
| Race* | | | |
| Black | 37.6 | 16.1 | 21.6 |
| Other | 8.4 | 8.3 | 11.6 |
| White | 54.0 | 75.6 | 66.8 |
| Income ^{*°} | | | |
| Less than \$10,000 | 25.7 | 17.7 | 28.0 |
| \$10,000 to \$14,999 | 10.8 | 7.1 | 9.2 |
| \$15,000 to \$19,999 | 6.9 | 4.6 | 8.0 |
| \$20,000 to \$24,999 | 9.0 | 8.0 | 10.8 |
| \$25,000 to \$34,999 | 10.5 | 10.0 | 13.5 |
| \$35,000 to \$49,999 | 8.0 | 9.2 | 6.2 |
| \$50,000 or more | 29.2 | 43.5 | 24.4 |
| Age | 26.5 (6.2) | 28.4 (6.5) | 25.7 (6.2) |
| Marital Status* | | | |
| Married | 53.4 | 73.3 | 61.7 |
| Timely PNC* | | | |
| Yes | 84.9 | 84.7 | 80.6 |
| No | 11.2 | 10.1 | 12.0 |
| Unknown | 3.9 | 5.2 | 7.4 |
| Smoker* | | | |
| Yes | 5.7 | 3.3 | 5.9 |
| Insured* | | | |
| Private | 41.9 | 60.8 | 40.0 |
| Medicaid | 55.6 | 34.6 | 51.9 |
| Other | 0.3 | 0.3 | 1.5 |
| Uninsured | 1.4 | 3.0 | 4.8 |
| Unknown | 0.8 | 1.3 | 1.8 |

 Table 2. Weighted Descriptive Statistics for Sample by HIV Test Status (%)

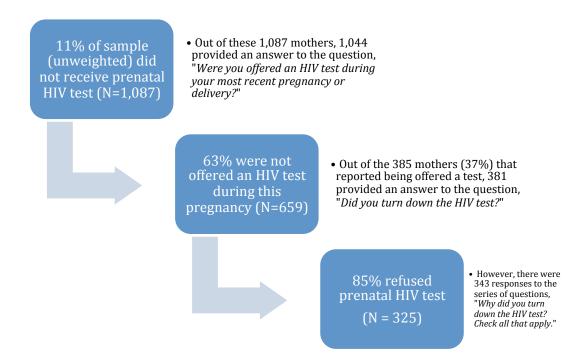
*Indicates statistically significant variation between the three groups at p<0.001

° 40% of sample missing; N=5,670

Descriptive Statistics – Sub-question Sample

In order to analyze the sub-question of this project, it was crucial to understand the sample of respondents. Depicted in Figure 2, the exclusion criteria for the subquestion sample was as follows: out of the 1,087 mothers who reported not receiving a prenatal HIV test, 1,044 provided an answer to the question, "Were you offered an HIV test during your most recent pregnancy or delivery?" Out of these 1,044 mothers, 659 mothers (63%) reported that they were *not* offered an HIV test during this pregnancy. Out of the 385 mothers (37%) that *did* report being offered a test, 381 provided an answer to the question, "Did you turn down the HIV test?" Out of those 381 mothers, 85% reported refusing their prenatal HIV test. Although 325 mothers reported opting-out, respondents were allowed to check multiple answer choices to the question of interest for the subanalysis. Thus, there were 343 responses to the question, "Why did you turn down the HIV test? Check all that apply."

Figure 2. Sub-question Sample Flow



Shown in Table 3, out of the 343 responses to the sub-question of interest, the vast majority of respondents reported refusing the prenatal HIV test for one of two reasons: having no self-perceived risk of HIV infection (47% of the sub-sample) or already having had a test prior to this pregnancy (43% of sub-sample). Only 3% of the sub-sample reported refusing the test due to fear of their test result, and less than 1% of the sub-sample refused because they did not want others to think they were at risk for HIV infection. An additional 6% of the sample reported refusing due to an "other" reason, which they wrote into the PRAMS questionnaire. Table 4 presents the list of "other" responses provided by mothers in the sub-sample.

| | Refused HIV test N=343 N (%) |
|--------------------|------------------------------------|
| Reason for Refusal | |
| Afraid of result | 11 (3.1) |
| Already tested | 152 (43.1) |
| Not at risk | 167 (47.3) |
| Other | 20 (5.7) |
| Secret | 3 (0.8) |

Table 3. Descriptive Statistics: Reasons for Refusal

Out of the 20 women who indicated refusal due to an "other" reason, 15 provided a fill-in answer to the question. Responses, seen in Table 3, included answers that corresponded to the initial sub-question categories, such as being tested previously (N=2), knowledge of negative sero-status (N=3) or having no self-perceived risk (N=1). Some women provided unique answers for refusal, including a fear of needles (N=1), the belief that their insurance did not cover the test (N=1), out-of-pocket costs (N=2), religious reasons (N=1), simply not wanting to (N=1), and knowing they were at risk for HIV infection, but continuing to refuse (N=1).

| Reason | N |
|---|----|
| Abstinence before marriage | 1 |
| Afraid of needles | 1 |
| Against religious beliefs to draw blood | 1 |
| Didn't think insurance covered test | 1 |
| Husband was just tested | 1 |
| Just did not want to | 1 |
| Knows they are HIV-negative | 3 |
| "I am not at all at risk" | 1 |
| Out-of-pocket cost too high | 2 |
| Tested previously | 2 |
| Thought she was at risk | 1 |
| Total | 15 |

Table 4. Reasons for Refusal – Responses to "Other"

Analysis – Main Question

In analyzing the main research question, whether maternal education level predicts a pregnant woman's receipt of prenatal HIV screening, we performed a multinomial logistic regression to determine the relationship between maternal education level and receipt of prenatal HIV test, controlling for a number of covariates. Table 5 provides the results, presented in marginal effects, of this regression.

| | (1) | (2) | (3) |
|---------------------------|---------------------------------------|------------------|--------------------|
| | HIV test: Yes | HIV test: No | HIV test: Unknown |
| Education Level | | P (| |
| Some HS or below | Ref | Ref | Ref |
| HS graduate (d) | 0.116 | -0.0100 | -0.106 |
| | (0.245) | (0.794) | (0.340) |
| Some college (d) | 0.108 | -0.0446 | -0.0638 |
| Some conege (u) | (0.372) | (0.212) | (0.629) |
| College graduate (d) | 0.159 | -0.0617 | -0.0975 |
| conege graduate (u) | (0.338) | (0.075) | (0.586) |
| Martana 1 A. | · · · · · · · · · · · · · · · · · · · | | ``´´´ |
| Maternal Age | -0.00106 (0.739) | -0.000994 (.) | 0.00205 (0.565) |
| Maternal Race | (0.757) | (.) | (0.505) |
| Black | Ref | Ref | Ref |
| DIACK | 1/11 | NC1 | NC1 |
| Other (d) | -0.176*** | 0.0144 | 0.162*** |
| Other (d) | | | |
| White (d) | (0.000) -0.159*** | (0.356) | (0.000) |
| White (d) | | 0.0520**** | 0.107*** |
| | (0.000) | (0.000) | (0.000) |
| Insurance Type | | | |
| Medicaid | Ref | Ref | Ref |
| | - | - * | - |
| Other (d) | -0.0822 | -0.0659^{*} | 0.148 |
| | (0.538) | (0.022) | (0.291) |
| Private (d) | -0.00407 | 0.0273** | -0.0232 |
| | (0.861) | (0.005) | (0.391) |
| Uninsured (d) | -0.160*** | 0.0218 | 0.138* |
| | (0.000) | (0.382) | (0.016) |
| Unknown (d) | (0.000) -0.702 ^{***} | -0.139*** | 0.841*** |
| | (0.000) | (0.000) | (0.000) |
| Timely PNC | (*****) | () | () |
| No | Ref | Ref | Ref |
| | - | - | - |
| Unknown (d) | -0.258*** | -0.0355* | 0.294^{***} |
| | (0.000) | (0.015) | (0.000) |
| Yes (d) | 0.0508 | -0.0218* | -0.0290 |
| | (0.078) | (0.050) | (0.385) |
| Marital Status (d) | -0.0533* | 0.0274** | 0.0259 |
| | (0.017) | (0.002) | (0.311) |
| Smoker (d) | 0.108** | -0.0194 | -0.0884* |
| | (0.003) | (0.102) | (0.027) |
| Age*Education Interaction | | | <u> </u> |
| Age*Some HS or below | Ref | Ref | Ref |
| - | - | - | - |
| Age*HS graduate | -0.00315 | 0.00129 | 0.00186 |
| 0 0 · | (0.435) | (0.430) | (0.683) |
| Age*Some college | -0.00162 | 0.00233 | -0.000707 |
| | (0.722) | (0.197) | (0.891) |
| Age*College graduate | -0.00183 | 0.00388* | -0.00205 |
| | (0.739) | (0.045) | (0.744) |
| Observations | 10018 | 10018 | 10018 |
| | | | |
| Conditional Mean | 0.4459 | 0.0929 | 0.4612 |

Table 5. Multinomial Regression Results for Main Question Analysis – Marginal Effects

Marginal effects; *p*-values in parentheses (d) for discrete change of dummy variable from 0 to 1 $p^* < 0.05$, $p^{**} < 0.01$, $p^{***} < 0.001$

Counter to our hypothesis, the primary independent variable, maternal education level, is not a predictor of a mother's prenatal HIV testing status.

Investigation of the covariates reveals a number of significant trends. Race plays a highly significant role in a woman's prenatal HIV testing status: compared to black women, white women are 5.2 percentage points more likely to not receive a prenatal HIV test at the conditional mean of 9%, as opposed to receiving a test or not reporting receipt. Additionally, white women and women whose race is categorized as "other" are more likely to have an unknown test status compared to black women (10.7 and 16.2 percentage points, respectively, at the conditional mean of 46%), as opposed to receiving a test or not receiving a test. All of these effects are statistically significant at p<0.001.

Not surprisingly, insurance type played a significant role in a woman's testing status. Compared to women covered by Medicaid, women with private insurance were 2.7 percentage points more likely to not receive a prenatal HIV test at the conditional mean of 9%, as opposed to receiving one or not reporting receipt (p<0.01). However, compared to women covered by Medicaid, women with "other" sources of insurance (e.g. Medicare, Title V Georgia Maternal Health Grant, etc.) were 6.6 percentage points more likely to not receive a prenatal HIV test at the conditional mean of 9%, as opposed to receiving receipt (p<0.05). Additionally, compared to women covered by Medicaid, uninsured women were 13.8 percentage points more likely to not receiving a test (p<0.05).

Additionally, timing of prenatal care receipt, marital status, and tobacco use during pregnancy were significant predictors of HIV testing status. Compared to women

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who did not initiate timely prenatal care, women who initiated timely prenatal care, or prenatal care before the second trimester of their pregnancy, are 2.2 percentage points less likely to *not* receive a prenatal HIV test at the conditional mean of 9%, as opposed to receiving one or not reporting receipt (p<0.05). Compared to unmarried women, married women are 2.7 percentage points more likely to *not* receive a prenatal HIV test at the conditional mean of 9%, as opposed to receiving one or not reporting receipt (p<0.05). Compared to unmarried women, married women are 2.7 percentage points more likely to *not* receive a prenatal HIV test at the conditional mean of 9%, as opposed to receiving one or not reporting receipt (p<0.01). Finally, women who used tobacco during their pregnancy are 11 percentage points more likely to receive a prenatal HIV test at the conditional mean of 45%, as opposed to not receiving one or not reporting receipt (p<0.01).

Analysis – Sub-question

In analyzing the sub-question, whether maternal education level predicts a pregnant woman's reason for opting out of prenatal HIV screening, we performed binary logistic regressions, using the sample model used in the main question analysis, on each of the five outcomes mentioned above: "I did not think I was at risk for HIV" (*risk*), "I did not want others to think I was at risk for HIV" (*secret*), "I was afraid of getting a test result" (*fear*), "I was tested before this pregnancy and didn't need to get another" (*need*), and "Other, please specify" (*other*). Due to extremely small success rates, three of the five variables, *secret* (N=3), *fear* (N=11), and *other* (N=20), were not regressed. Two of the five variables, *risk* and *need*, were analyzed, and their results are displayed in Tables 6 and 7, respectively. Two of the insurance categories, "Other" and "Unknown," were dropped in both of these analyses due to collinearity issues.

| | (1) Not at risk |
|----------------------|-------------------------------|
| Education Level | INOU AUTISK |
| Some HS or below | Ref |
| Some HS of below | - |
| HS graduate | 0.146 |
| | (0.414) |
| Some college | 1.530 |
| Some conege | (0.858) |
| College graduate | 0.737 |
| conege graduate | (0.896) |
| Maternal Age | 0.982 |
| maternal fige | (0.826) |
| Maternal Race | (0.020) |
| Black | Dof |
| DIACK | Ref |
| Other | 2.148 |
| Otilei | (0.139) |
| White | (0.139) 1.769 [*] |
| white | |
| I T | (0.078) |
| Insurance Type | D.C |
| Medicaid | Ref |
| | - |
| Private | 0.899 |
| | (0.764) |
| Uninsured | 1.959 |
| | (0.426) |
| Timely PNC | D (|
| No | Ref |
| | - |
| Unknown | 1.509 |
| | (0.578) |
| Yes | 1.668 |
| | (0.364) |
| Marital Status | 1.865 |
| ~ 1 | (0.139) |
| Smoker | 0.452 |
| | (0.216) |
| Age*Education Intrxn | |
| Age*Some HS or below | Ref |
| | - |
| Age*HS graduate | 1.084 |
| | (0.401) |
| Age*Some college | 0.982 |
| | (0.848) |
| Age*College graduate | 1.015 |
| | (0.873) |
| Observations | 343 |

Table 6. Logistic Regression Results for Sub-question Analysis – Risk Odds Ratios

Exponentiated coefficients; p-values in parentheses p < 0.10, ** p < 0.05, *** p < 0.01

The regression of maternal education level on the likelihood of a woman refusing a prenatal HIV test due to no self-perceived risk, seen in Table 6, did not indicate a clear relationship between the two variables. However, race was a significant predictor: white mothers were 77% more likely to report refusal due to no self-perceived risk compared to black mothers. No other covariates were statistically significant.

| | (1) |
|----------------------|----------|
| | Need |
| Education Level | Def |
| Some HS or below | Ref |
| HS graduate | 4.863 |
| 115 graduate | (0.540) |
| Some college | 0.621 |
| Some conege | (0.857) |
| College graduate | 4.198 |
| Conege graduate | (0.577) |
| Maternal Age | 1.049 |
| maternat fige | (0.605) |
| Maternal Race | (0.000) |
| Black | Ref |
| Ditter | - |
| Other | 0.522 |
| | (0.215) |
| White | 0.740 |
| () Inte | (0.349) |
| Insurance Type | (0.5 17) |
| Medicaid | Ref |
| i))ouloulu | - |
| Private | 1.332 |
| 1 II valo | (0.417) |
| Uninsured | 0.645 |
| | (0.622) |
| Timely PNC | |
| No | Ref |
| | - |
| Unknown | 0.472 |
| | (0.351) |
| Yes | 1.320 |
| | (0.621) |
| Marital Status | 1.301 |
| | (0.526) |
| Smoker | 2.227 |
| | (0.198) |
| Age*Education Intrxn | |
| Age*Some HS or below | Ref |
| | - |
| Age*HS graduate | 0.960 |
| - | (0.688) |
| Age*Some college | 1.038 |
| - | (0.713) |
| Age*College graduate | 0.971 |
| | (0.764) |
| Observations | 343 |
| | |

Table 7. Logistic Regression Results for Sub-question Analysis – Need Odds Ratios

Exponentiated coefficients; p-values in parentheses p < 0.10, ** p < 0.05, *** p < 0.01

The regression of maternal education level on the likelihood of a woman refusing a prenatal HIV test due to already having been tested, seen in Table 7, again did not indicate a clear relationship between the two variables. No covariates were statistically significant.

Discussion

Counter to our hypothesis, analysis of the main research question suggests that maternal education level does not predict a woman's HIV testing status. However, demographic characteristics are important predictors of prenatal HIV testing behaviors. Analysis of the research sub-question showed no clear relationship between maternal education level and a woman's likelihood of a woman refusing a prenatal HIV test due to already having been tested or no self-perceived risk. Race was a significant predictor of a woman's likelihood of refusing a prenatal HIV test due to no self-perceived risk.

Adapting Cox's IMCHB theoretical framework to the context of this project provided a sound rationale for the research questions. Although there were many factors that were not able to be included in the analysis due to immeasurability and data constraints, the framework provided a clear theoretical pathway that linked elements of patient singularity (i.e. maternal education level) to health outcomes (i.e. utilization of prenatal HIV screening). Ultimately, employing this framework helped provide an insight into the factors that influence patient health behavior regarding acceptance of prenatal HIV testing.

Implications

In spite of the research findings not supporting our hypotheses, this study contributes important information to existing literature about the receipt of prenatal HIV testing in the United States. As one of the main strategies for prevention of mother-tochild transmission (MTCT), the importance of prenatal HIV testing cannot be overstated. Our results of this project offer five notable contributions to existing prenatal HIV testing knowledge. First, 11% of the sample reported that they did not receive an HIV test during their most recent pregnancy, and 38% of the sample did not report whether they received or did not receive a prenatal HIV test. Consistent with literature, this number provides further evidence that universal HIV screening among pregnant women is not occurring in the United States [6, 23, 31, 40].

Second, the three groups of women in this sample – those who reported receiving a prenatal HIV test, those who reported not receiving a prenatal HIV test, and those who did not report their receipt of a prenatal HIV test- varied significantly by demographics. A larger portion of women in the group not receiving the test were white, married, higher educated, privately insured, and making \$50,000 or more compared to the other two groups. Additionally, a larger portion of women in the group not reporting their testing status were white, lower educated, and poor, with higher rates of smoking and lower rates of timely prenatal care compared to the other two groups. These outcomes paint a tentative demographic picture of women who are not receiving prenatal HIV tests: white, married, college-educated women in the middle-class with private health insurance. A majority of these characteristics have been previously associated with refusal of HIV testing. Multiple studies have indicated that the demographic factors associated with refusal are older age, white race, female sex, higher income, and being married [66-68]. Although our results confirm those reported previously, they introduce the education component, which had not previously been explored among pregnant women.

Additionally, we gain insight into women who are not reporting HIV testing status, who were more likely to be lower educated, low-income white women with high-risk health behaviors such as smoking and delaying prenatal care. To date, no reported studies explore the characteristics of women who fail to report HIV testing on household surveys and the implications it may have on estimates of HIV testing rates in the United States. However, research has indicated that the demographic of postpartum mothers who do not report their *income* on population-based surveys closely match the women in this study who did not report their HIV status: they are more likely to be younger, less educated, unmarried, and delay prenatal care [69].

Third, multinomial logistic regression showed that maternal race, primary source of insurance, and marital status, *not* education level, were significant predictors of a woman's prenatal HIV testing status. White, married, privately insured women were statistically more likely to not receive a prenatal HIV test. White women, "other" women, and uninsured women were statistically more likely to not report prenatal HIV testing status. These results lend additional evidence to the demographic "pictures" developed above. Because over 40% of the sample did not include their income data, an income variable was excluded from our regressions; thus, insurance status may function as a proxy for income. Almost all other demographic characteristics were significant predictors of testing status; thus, it is remarkable that education level was *not* a predictor for any of the three groups. Exploring the relationship between education level and receipt of HIV testing does not account for other factors that influence a woman's receipt of the test, such as institutional behavior, individual provider practice, or patient-provider communication. A richer understanding of the experiences of pregnant women in the

health care system is needed to understand the range of factors that influence their receipt of prenatal HIV testing.

Fourth, white women were more likely to opt-out of prenatal HIV testing due to the assumption that they were not at risk for HIV transmission. Literature supports this standpoint, as out of all demographic groups at risk for HIV infection, white heterosexual women have one of the lowest likelihoods for transmission [70]. When one begins to think about the reasons behind the assumption held by these women, the underlying reasons are vague. Do white women assume that they are low-risk for HIV due to their *personal* risk factors? Or, do white women assume that they are low-risk simply because HIV has been more prevalent amongst males and minority groups? Alternatively, do white women assume that they are low-risk because they do not believe HIV is a health issue about which they should be concerned? Concern over HIV/AIDS has lost salience with the general public, and in 2011 less than half of surveyed Americans reported having heard "something" about the domestic HIV/AIDS epidemic [71, 72]. Unfortunately, due to the limited scope of the PRAMS dataset, these intricate distinctions cannot be teased out here.

Finally, the fifth element involves the responses provided by women choosing the "other" option of the question, "Why did you turn down the HIV test? Check all that apply" (seen in Table 3). Many of the provided responses coincide with those previously reported in literature: the belief that insurance would not cover the test; prior testing or knowledge of HIV status; having no self-perceived risk; and exceedingly high out-of-pocket costs of testing [3, 14, 39]. However, some were unique to the sample but corresponded to larger social trends within the national HIV epidemic: abstinence before

marriage, which assumes both monogamy, that *both* parties practiced abstinence before marriage, and that the couple is not serodiscordant (i.e. having different HIV statuses); fear of needles, thus not wanting to have blood drawn for the test; religious beliefs against drawing blood; partner was just tested, which again assumes monogamy, fidelity, and seroconcordance; and the belief that they were at risk, but still refused testing, possibly out of fear. Particularly important to the context of HIV testing examined here is the assumption that monogamy denotes low-risk. Because sexual encounters inherently involve two or more individuals, any one sexually active individual can only speak for their own sexual experiences. Interestingly, literature shows that concern about their partners' report of sexual behaviors, HIV status, and testing history has been cause for women to *seek* HIV testing in the past [73]. Although monogamy is often considered to be a low risk sexual behavior, a woman's monogamy with her partner or husband cannot pigeonhole her as being low-risk for HIV [66, 74, 75]. Additionally, a common response to HIV testing is fear. Fear motivates some individuals to *not* receive an HIV test, for the psychological ramifications of a diagnosis can cause patients to prefer an ambiguous HIV status rather than risk receiving a positive result [66]. Patients may also refuse testing due to the potential psychological ramifications of receiving a false-positive test result [76].

Clinical Implications

Literature shows that the general public's knowledge about HIV/AIDS is suboptimal. Research surveying the public's knowledge about HIV transmission routes show that a surprising proportion of adults either lack basic knowledge of HIV transmission or believe that HIV can be transmitted though casual social contact (e.g. shaking hands, sharing a drinking glass) [73, 77, 78]. In a study of 851 female patients, only 2% reported a self-perceived high risk for HIV transmission, despite over half of the sample reporting unprotected sex with more than one partner [79]. This lack of knowledge has serious implications for women in their decision to receive a prenatal HIV test; if women are inaccurately perceiving their own risk factors and assuming themselves not to be at risk, as many of the women in this sample reported, they could be voluntarily neglecting a strategy for prevention of MTCT. Another significant factor influencing a woman's testing decision is the opinion of her health care provider, which includes her provider's perception of risk. However, healthcare providers do not necessarily have accurate knowledge of HIV risk factors or current HIV testing policies. Surveys of obstetric providers have shown that fewer than 50% of providers correctly named the most common modes of transmission among women, HIV epidemiology among women of childbearing age, HIV testing guidelines, and the difference between HIV and AIDS [80-82]. Thus, we cannot assume that all obstetric providers have the knowledge to provide satisfactory advice to female patients regarding their decision to receive a prenatal HIV test.

In order to better inform both patients and providers, comprehensive education should be recommended for providers who, in turn, will equip their patients with the information necessary to make informed decisions. Educational interventions such as "Ask, Screen, Intervene (ASI)," a program commissioned by the CDC to train healthcare providers in conducting risk assessment and prevention counseling for HIV-positive patients, could be introduced among obstetric, gynecologic, and family planning providers to address these knowledge gaps in their care of both pregnant and nonpregnant women and girls [83]. Components of the program include Behavioral Risk and STD Screening, Universal Prevention Messages and Addressing Misconceptions, Tailored Behavioral Interventions, and Partner Services [83]. Completion of this program has produced increased self-efficacy and confidence among providers when asking about risk behaviors, addressing misconceptions about HIV transmission, delivering tailored prevention messages, and describing and utilizing partner services [83]. In a clinical setting, every pregnant mother should have access to both informed providers and knowledge about their own personal risk factors in order to promote truly informed decisions regarding acceptance of prenatal HIV testing.

Policy Implications

Ultimately, the first prevention strategy of MTCT, prenatal HIV testing, is not being universally accomplished among pregnant women within the United States. Although some public health leaders claim that perinatal HIV/AIDS has been "virtually eliminated" in the US, the 150-350 infants who are born each year with HIV suggest otherwise [29]. This begs the question, is opt-out prenatal HIV testing enough? While shifting from opt-in policies to opt-out policies has increased the number of pregnant women receiving prenatal HIV testing, is opt-out HIV testing enough to provide mothers with the resources to make informed decisions about their personal risk for HIV transmission [10, 33, 84]? Rather than focusing solely on reforming testing guidelines, HIV/AIDS prevention resources and funding should be focused more towards provider education, through programs such as ASI, as a means to address the lack of universal screening of pregnant women in the United States.

Alternatively, policy makers and health care providers could push for insurance companies to provide increased coverage of sexually transmitted infection (STI) and HIV

counseling. Provision of high-intensity behavioral counseling to all sexually active adolescents and adults - at little to no cost sharing - would promote prevention of the transmission of HIV and other STIs. Currently, only 39 out of the 50 state Medicaid programs cover STI counseling under reproductive health and family planning services [85]. Providing coverage of these services would help in the prevention of HIV and STIs nationally, giving women access to providers who can help them make safer choices and informed decisions about their HIV and STI screening. At present, Georgia's Medicaid program *does* cover STI screening, but does so with cost sharing as a reproductive health service and no patient cost sharing as a family planning service. Fortunately, the preventive services provision of the Patient Protection and Affordable Care Act (ACA) requires all health care plans to cover STI prevention counseling and HIV counseling to all women with *no* patient cost sharing [86]. It remains to be seen whether insurance providers, health care providers and patients will capitalize on this service as the ACA continues to roll out, and further research should analyze rates of HIV and STI counseling among sexually active individuals as data becomes available.

Limitations

Although this project shed light on the culture of HIV testing among pregnant women in Georgia, there are a number of important limitations that must be addressed. First, there is limited generalizability of these results to the national population of pregnant women, as the data is from one Southeastern state. Our findings are representative of the population of pregnant women in Georgia from 2004 to 2008, and may not be generalizable to other states, particularly those outside of the Southeast. Additionally, variations in state HIV testing policy may influence the proportion of women receiving prenatal HIV tests; because Georgia's opt-out policy legislation was not signed into law until 2007, states utilizing an opt-out approach for a longer period of time may reduce the number of women not receiving prenatal HIV tests [87].

Second, the PRAMS dataset itself faces limitations. A majority of PRAMS data is self-reported, and all data are reported retrospectively. Some demographic information is taken directly from a child's birth certificate, but each mother self-reports the remainder of the information in the 2 to 4 months following the birth of her child. Because of this, there may be recall bias in the data that could influence results. For example, a mother may remember refusing an HIV test but, upon completion of the survey, may not explicitly remember her reason for doing so. Additionally, opt-out HIV testing policy is often implemented in such a way that mothers are not *explicitly* asked if they want an HIV test; it is simply included in the battery of tests. Accordingly, women may not remember or be aware of whether they were tested for HIV during their pregnancy, and may assume that they did not receive a test. Thus, there may be over- or under-estimation of the proportion of women not receiving a prenatal HIV test. Furthermore, social desirability may have influenced participants' responses to the questions. Social desirability refers to the tendency of some respondents to report the answer that they deem to be most "socially desirable," rather than their true answer [88, 89]. Since HIV has a history wrought with stigmatization, it is possible that participants reported receiving or not receiving a prenatal HIV test in order to discourage discrimination [72, 90]. Finally, a challenge with self-report data is the ability for women to opt-out of questions. This impeded our data analysis, as approximately one-sixth of the sample did not report income data. With such a large proportion of the sample having missing

income data, we were not able to include income as a covariate in our regressions, which may have introduced bias into our estimates.

Third, because this survey focuses on mothers, PRAMS data does not capture any aspects of the provider's practices or opinions. As discussed above, provider-patient interaction is an essential component of an individual's healthcare experience that also influences health outcomes. Depending on provider preference, some providers may explicitly inform patients that a prenatal HIV test is included in the routine battery of tests during a prenatal care visit; others may not. This may effect whether a woman was overtly aware of her acceptance or refusal of an HIV test, and thus affect her response to the question determining the primary dependent variable, "at any time during your most recent pregnancy or delivery, did you have a test for HIV (the virus that causes AIDS)?" However, because PRAMS does not collect any data on behalf of the providers, this provider-level information is unavailable.

Fourth, the data used in this analysis was from Phase 5 of PRAMS, collected from 2004 to 2008. The earliest year of data is now a decade old, and this time period bridges the major shift from opt-in to opt-out HIV testing policy. Because the data analyzed here contain only one year of data post-adoption of the opt-out policy in Georgia, they do not provide enough information to securely assess the effect of the policy change. Assuming that an opt-out prenatal HIV testing policy has been more widely adopted in recent years, comparing current data to Phase 5 data would more accurately depict the outcomes from the 2006 policy change.

Fifth, and most importantly, there is a fine line between opt-in and opt-out prenatal HIV testing procedures in clinical practice. Although the CDC began

recommending opt-out HIV testing programs for pregnant women in 2006, an opt-out policy was not signed into law in Georgia until 2007. Thus, a majority of the sample (which was from 2004 to 2008) was most likely operating under an opt-in system. However, the American College of Obstetrics and Gynecology (ACOG) has been recommending an opt-out system since the early 2000s. Therefore, if providers have been using an opt-out system for a longer period of time, it is not clear based on the PRAMS data whether women were truly knowledgeable about their acceptance or refusal of prenatal HIV test, or whether they were simply being offered without explicit notification. As described earlier, under opt-in guidelines, informed consent was required for HIV testing. Under opt-out guidelines, providers may not plainly offer the test; it is included in the battery of tests, and each woman has the right to decline if she wishes. Therefore, under the opt-out system, women may be less likely to refuse a test simply because they aren't explicitly aware that it is happening, and refusing the test requires more effort under the opt-out system. Unfortunately, these are nuances that we are unable to distinguish.

Future Research

In order to further examine the state of prenatal HIV testing in the United States, research should first utilize more recent data from the PRAMS dataset. Phase 6 of the PRAMS survey began in 2009 and is currently in the field [61]. Upon release of more recent data, one could assess the current state of prenatal HIV testing as well as perform an unbalanced longitudinal comparison of testing rates before and after the 2006 opt-out policy recommendation. Further analyses should include geographic variables to determine the differences in HIV testing rates by zip code, focusing on the differences

between rural and urban areas. Geographically identifying zip codes with low testing acceptance rates would permit researchers and policy makers to target interventions to providers and patients in these areas. Additionally, research should expand to a nationwide analysis. This would eliminate the limited generalizability faced in the current project by analyzing data from one Southeastern state. It would also provide insight into the success of the CDC's opt-out policy recommendation on a national scale.

As mentioned previously, one of the largest barriers to understanding the experience of women when they consider prenatal HIV testing is the absence of knowledge about provider practice. Future research could combine the quantitative analysis of PRAMS data with qualitative interviews with a diverse group of obstetric providers in order to understand how clinicians approach prenatal HIV testing. Doing so would provide the insight into provider practices and institutional regulations that is absent in the current analysis. Additionally, a quantitative survey of obstetric providers could be undertaken to assess provider practices and knowledge of HIV testing guidelines on a broader scale. As mentioned previously in the chapter, adoption of an education program for providers could be expanded to focus on obstetric and gynecologic providers. Further research could analyze the success of implementing such a program in the prenatal care setting, assessing whether targeted HIV education interventions improve the knowledge of health care providers and patients and promote informed decision making in regards to prenatal HIV testing.

Conclusion

This study contributes to the existing literature on the predictors of prenatal HIV screening receipt in the United States. Rather than maternal education level predicting a

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woman's receipt of a prenatal HIV test, demographic factors are the key predictors of prenatal HIV testing receipt among pregnant women. Exploring these characteristics has provided a general picture of women who are not receiving prenatal HIV screening and those whose who do not report HIV testing status. Although the CDC's 2006 opt-out HIV screening policy recommendation has increased rates HIV testing among pregnant women, these findings indicate that universal HIV screening during pregnancy is not being achieved in the United States. Efforts to continue to reduce the number of perinatal HIV cases reported each year in the United States should further emphasize patient and provider education programs along with insurance coverage of HIV and STI counseling services.

The findings of this study should invite further research on the shared decision making practices between pregnant women and their providers. In addition to employing a more expansive series of years and expanding analysis to a national level, future research should utilize a mixed methodology in order to provide quantitative and qualitative data on the experience of pregnant women, their providers, and the prenatal HIV screening decision-making process.

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