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The Influence of Postpartum Retention

in Care on Mortality in Women Living with

HIV

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### Abstract

## The Influence of Postpartum Retention in Care on Mortality in Women Living with HIV By Jade McBroom

Postpartum women living with HIV have been found to have poor retention in care and may be at greater risk for mortality and morbidity in comparison to their HIV negative counterparts. In addition, the evidence of worse outcomes within Southern states of higher HIV morbidity and mortality warrants further investigation. Therefore, the purpose of this investigation was to describe mortality and retention in care as well as factors impacting retention in care, viral suppression, and mortality using the Andersen Behavioral Model. Data was from the Women's Interagency HIV Study, a national, longitudinal, epidemiological cohort study. Participants (n=283) were HIV positive females, of child-bearing age who had a live birth post enrollment. Retention was adaptively defined as two healthcare visits in a twelve-month period. Survival analysis was used to examine mortality. Logistic regression modeling was used to examine predisposing and enabling factors including age, race, marital status, education, income/employment, depression, substance use, social support, housing, and health insurance coverage. Rates of having an optimal outcome (retained and virally suppressed) remained steady at around 25% over the ten-year period. Nearly 15% of the participants experienced mortality during the study period. Participants who were not married, had an income of \$18,000 or less, no social support, did not live in their own house or apartment, and no reported insurance coverage significantly decreased the odds of being retained over time. High income and no history of substance use were found to be protective against mortality. Lastly, retention did not have a significant association or impact on mortality. Findings suggest that both predisposing and enabling factors influence retention, but the directions of these associations vary depending on which outcome is examined and which postpartum year. Regional differences were difficult to analyze related to the small Southern sample size (n=11). Efforts to increase retention should focus on enabling factors such as insurance and housing that can be changed rather than predisposing factors. Future interventions could also target postpartum engagement especially in the first year postpartum to encourage lifelong retention and HIV viral suppression to prevent poor outcomes like mortality.

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### **Chapter 1: Introduction**

In the United States, approximately one in four people living with HIV are women. Nearly 64% of those women received care for HIV, according to the Centers for Disease Control and Prevention (CDC, 2016d). However, only half of those women are retained in care, and of that half, only 48% of them are virally suppressed. Furthermore, AIDS-related illness remains the number one cause of death among women of reproductive age worldwide (15-44 years per AIDS Virus Education Research Trust) (Avert, 2018). Although many factors are associated with these HIV outcomes, clear underlying causes have yet to be determined. Meditz and colleagues (2011) found that despite women having favorable clinical factors initially, female HIV-1 seroconverters had worse outcomes than their male counterparts. Even more disturbing is that elevated morbidity was associated with being non-white and residing in the southern United States (Meditz et al., 2011). These poor outcomes can be further exacerbated during pregnancy and the postpartum period.

After delivering a baby, women living with HIV (WLWH) are less likely to adhere to optimal HIV care, which is defined as at least 2 HIV care visits at least three months apart in one year (Georgia Department of Public Health, 2019). Postpartum retention in HIV care, which refers to reestablishing HIV care after delivery, has been identified as a significant predictor of long-term retention in care and viral suppression (Adams et al., 2015). Maintaining virologic control can improve outcomes not only related to pregnancy but also in terms of HIV-related illnesses, such as infant outcomes, mortality, and opportunistic infections. A study conducted in Mississippi found 12% of postpartum women living with HIV died within a median time of five years post-delivery (Rana et al., 2016). Although there has been a proliferation of studies on the

effects of retention in care on clinical outcomes in people living with HIV in general, few studies have been conducted on the relationship between postpartum retention in care and HIV-related clinical outcomes.

It is imperative to better understand the multitude of factors associated with HIV mortality, such as HIV disease progression and demographic and socioeconomic factors, such as race and poverty. Several socioeconomic factors may independently contribute to the development of comorbid diseases such as cardiovascular disease and diabetes; in other words, these comorbidities may not be HIV-related. Lorenc et al reported in a study of HIV patients and comorbid conditions, that antiretroviral toxicity could contribute to diabetes and cardiovascular disease (Lorenc et al., 2014). One of the hypothesized pathways for antiretroviral therapy to increase risk for diabetes and cardiovascular disease is through lipid derangement However, race and economic status are also risk factors for these diseases, and as such HIV infection itself may not be the only contributing factor. Socioeconomic factors may contribute to the likelihood of WLWH being retained in care when disease severity, poverty, or multiple diseases change the type (outpatient -versus inpatient care) and level of care needed (simple office follow-up versus intensive medication therapy). These risk factors must be further examined within this vulnerable population.

### **Statement of the Problem**

**Perinatal HIV exposure.** Nearly 8,500 pregnant women deliver each year in the United States (CDC, 2016b). Advancements in health care have reduced the chances that an infant will contract HIV when the mother is HIV positive. However, without treatment, 25% percent of infants born to WLWH will also be infected. Antiretroviral therapy (ART), cesarean delivery, and refraining from breastfeeding reduce the risk of transmission to less than two percent (U.S.

Department of Health and Human Services [USDHHS], 2018). Although this is excellent news for infants, this does influence a mother's decision not to continue to seek treatment for herself. Clouse and colleagues found that 29% of HIV health care worker respondents indicated that mother's care is about their baby's health more than their own (Clouse et al., 2014). One worker specifically said, *"When they see that their babies are well, they don't see a need to come to the clinic anymore (Clouse et al., 2014)."* This attitude is disheartening in an age of quality HIV care.

**History of HIV in Pregnancy.** In 1987, the U.S. Food and Drug Administration approved the drug azathioprine , aka zidovudine, as the first drug to treat HIV (Office on Women's Health in the U.S. Department of Health and Human Services, 2018). Treatment with this drug slowed disease progression and prevented transmission to infants in HIV-positive pregnant women. This pivotal drug prompted the U.S. Public Health Service in 1994 to recommend that HIV-positive pregnant women receive azathioprine to reduce perinatal transmission. In 2003, this recommendation was updated to make HIV testing a routine part of medical care and prenatal testing. Current guidelines now recommend combination antiretroviral therapy during pregnancy for the health of the mother and the prevention of mother-to-child transmission (AIDSinfo, 2016).

This intensive testing and monitoring are lacking within the postpartum period. This current issue does pertain to only WLWH. The American College of Obstetricians and Gynecologists (ACOG) in 2018 reemphasized the importance of the postpartum period, or "fourth trimester," as a time to reduce severe maternal morbidity and mortality (ACOG, 2018). American College of Obstetricians and Gynecologists 's recommendations now include check-ups for women within the first three weeks postpartum rather than six. Furthermore, American

College of Obstetricians and Gynecologists encourages timely follow-up, particularly for women with chronic medical conditions such as HIV. A comprehensive postpartum visit no later than 12 weeks postpartum will help women with chronic conditions to transition to ongoing well-woman care and will provide individualized follow-up. In cases of WLWH, the postpartum period offers an opportunity to optimize women's health care, especially comprehensive health care. Comprehensive health care for WLWH includes "primary, gynecologic/obstetric, and HIV specialty care for the woman with HIV; pediatric care for her infant; family planning services; mental health services; substance abuse treatment; support services; coordination of care through case management for a woman, her child(ren), and other family members; and prevention of secondary transmission for serodiscordant partners, including counseling on the use of condoms, antiretroviral therapy to maintain virologic suppression in the partner with HIV (i.e., treatment as prevention), and potential use of pre-exposure prophylaxis by the partner without HIV" (Panel on Treatment of Pregnant Women With HIV Infection and Prevention of Perinatal Transmission, 2017). This comprehensive model is desired because a partnership between obstetrics, gynecology, and internal medicine can improve outcomes and care transition. Support services may include housing, transportation, and respite care, and such services should begin before pregnancy and continue throughout and after pregnancy. Despite these goals for optimized care, many women, both HIV-positive, and uninfected, are not attending postpartum visits. Current estimates within the U.S. are that 40% of women do not attend a postpartum visit after birth (ACOG Communication Office, 2018).

Further complicating these optimized goals are that many of the components of comprehensive care are not located within the same practice or health system for WLWH. Case management helps to alleviate this issue by optimizing the care within the postpartum period to ensure that WLWH continue antiretroviral therapy post-delivery. Clinical guidelines recommend special hospital programs to dispense antiretroviral therapy to WLWH before discharge from the hospital post-delivery. The benefits of these programs and care coordination include better continuity of care, immune function, and viral suppression (Brennan-Ing et al., 2016; Irvine et al., 2014). Postpartum counseling for WLWH emphasizes the need to continue antiretroviral therapy and reduce the risk of sexual transmission.

**Pregnancy and HIV treatment adherence.** Some critical concepts must be defined to understand better the role of pregnancy and the path from HIV diagnosis to viral suppression, commonly known as the HIV care continuum. Continuum of HIV care is a conceptual model that identifies the spectrum of HIV care. The spectrum includes a range of individuals, from those who do not know they are infected to those who are fully retained in care. Testing is the earliest point at which to enter the continuum; an essential step to the overall goal for WLWH to be linked to care as early as possible after diagnosis, started on antiretroviral therapy, and then fully retained in care.

Retention in care refers to a patient's regular engagement with a health care system after initial entry. Typical conceptualizations are based on missed appointments or medical visits at regular, distinct intervals. While attempts have been made to determine the percentage of the HIV-positive population retained in care, the numbers vary from as low as 40% to as high as 75% (Joint United Nations Programme on HIV/AIDS, 2014; University of Washington and the AETC National Coordinating Resource Center, 2018).

Overall, the most common risk factors for decreased retention in care include non-white race/ethnicity, men who have sex with women orientation, young age, uninsured or underinsured status, active substance use disorder, mental illness, healthy status perception, unmet needs, and

place of residence (University of Washington and the AETC National Coordinating Resource Center, 2018, pp. 3-4). The risk factors a person has can influence how well they progress through the different stages of the continuum.

*Stages of HIV Care Continuum*. Diagnosis is the first step in the continuum. Current CDC guidelines recommend that health care providers offer patients between 13 and 64 years of age an HIV test at least once (Branson et al., 2006). As stated earlier, guidelines for pregnant women recommend testing at least once within the first trimester and again in the third trimester in high prevalence areas. These efforts help link the patient to HIV medical care.

Linkage to care is defined as entering and staying in HIV medical care (US Department of Health and Human Services, 2018). Optimum linkage to care refers to a period of time no greater than three months between diagnosis and the initiation of treatment with an HIV care provider (Spicer & Ford, 2012). Rates of linkage to HIV medical care in the U.S. are encouraging. Seventy-five percent of HIV-positive individuals are linked to care with women demonstrating congruence at 76.4% (CDC, 2016c). The final stage of this continuum is prescription for antiretroviral therapy and suppressing the virus below 200 copies per milliliter (Grulich et al.; Rodger et al., 2016). Patients must be retained in care in order to reach this final stage The retention-in-care stage, which is defined in this paper as two HIV care visits per year with visits at least three months apart, is the stage of the continuum that this research proposes to examine.

**Definitions of Retention in Care, Estimates, and Limitations of Measuring.** As stated earlier, there are several ways to measure retention in care. The four most common measures are "appointment adherence defined as not missing greater than three appointments out of 10 in one's lifetime, appointment consistency, missed visits, and gaps in care (Nwabuo et al., 2014; University of Washington and the AETC National Coordinating Resource Center, 2018, p. 16)". The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) revised performance measures in 2013. Based on this revision, the Institute of Medicine has defined retention in care as "at least two medical visits every 12 months, with a minimum of 90 days between visits" (HRSA, 2017; Rebeiro et al., 2014). Due to the nature of the measurements, careful surveillance techniques are necessary to determine who is retained in care (Risher et al., 2017). These measurement processes are essential to understand because poor retention in care impacts clinical outcomes, such as mortality, the rate of virologic suppression, and HIV transmission.

HIV-positive patients who are not retained in care (and who are less likely to have the virus suppressed) are responsible for 60% of all HIV transmissions in the United States (University of Washington and the AETC National Coordinating Resource Center, 2018). In other words, patients who are retained in care or receive more HIV medical care are more likely to be virally suppressed. This status of viral suppression is related to careful monitoring of viral load levels to make sure they are responding to antiretroviral therapy but also increased intervention if their viral loads are trending upward. WLWH could receive HIV care appropriately and not necessarily be virally suppressed, possibly due to nonadherence with antiretroviral therapy as prescribed, having other comorbidities that make it difficult for their viral load levels to be controlled, or experience resistance to antiretroviral drugs. Due to these intricacies, understanding the HIV Care Continuum in specific populations is vital for optimizing care.

HIV Care Continuum and Women. Overall, women perform slightly better than men in most stages of the care continuum, although both men and women have low rates of viral

suppression. Figure 1, developed and sourced from the CDC following agency public domain guidelines, compares the continuum by sex from diagnosis to viral suppression.



# Persons Living with Diagnosed or Undiagnosed HIV Infection HIV Care Continuum Outcomes, by Sex, 2018—United States



Note: Source: CDC"; "Materials developed by CDC" Reference to specific commercial products, manufacturers, companies, or trademarks does not constitute its endorsement or recommendation by the U.S. Government, Department of Health and Human Services, or Centers for Disease Control and Prevention. Material is otherwise available on the agency website for no charge.

Barriers to retention in care for women align with the general barriers listed earlier (e.g., lack of transportation, lack of insurance). However, barriers more specific to women include childcare issues, mistrust of health care providers, inability to take time off from work, poverty, and residing in rural areas (Aziz & Smith, 2011). Barriers to antiretroviral therapy initiation are also similar to the factors that predispose people to HIV transmission, such as drug use, low educational level, physical/sexual abuse, and depression. In summary, many of the social risk

factors that place women at a higher risk for HIV contribute to them not getting tested, presenting late to care, not being retained in care, and not adhering to antiretroviral therapy. These care failures can further exacerbate treatment adherence during this period.

### Postpartum, HIV-positive women's challenges with treatment adherence.

Understanding adherence to antiretroviral therapy in the postpartum period is complicated by several challenges, including the difficulty of medical appointment follow-up, access to insurance, postpartum depression, and physical and psychological changes in the postpartum period (Momplaisir, Storm, et al., 2018). Caring for a new baby, along with these challenges, can make retention in care difficult. The consequences of poor antiretroviral therapy adherence include lack of viral suppression, development of drug resistance, opportunistic infections, increased risk of transmission, and decreased long-term effectiveness of antiretroviral therapy (Le et al., 2001; Murri et al., 2000; Panel on Treatment of Pregnant Women With HIV Infection and Prevention of Perinatal Transmission, 2017; Paterson et al., 2000). Early diagnosis of pregnancy and active engagement in care during and after pregnancy are essential (Nijhawan, 2017) to avoid these consequences.

Multiple studies have examined the factors that improve clinical outcomes, such as viral suppression in postpartum WLWH. Adams and colleagues (2015) conducted a retrospective analysis of 561 HIV-positive postpartum women in Philadelphia. They found that only 38% were retained in care ( $\geq$ 1 CD4 count or viral load. test in each 6-month interval of the period with  $\geq$ 60 days between tests) three months post-delivery (Adams et al., 2015). Their study focused on long-term outcomes at one and two years postpartum. Engagement in care ( $\geq$ 1 CD4 count or viral load test within 90 days of delivery) during pregnancy was high (92%) when compared to the postpartum period (38%). Engagement in care within 90 days of delivery was associated with

significantly increased chances of retention after five months. This study suggests that there is a narrow window of opportunity within the early postpartum period to keep women retained in care. Strategies that have been shown to improve postpartum retention in care include telephone and home follow-ups and initiating antiretroviral therapy during pregnancy (Leach-Lemens, 2016a, 2016b). Although these patient-level factors and interventions can greatly influence postpartum retention in care, WLWH in the southeastern part of the U.S. have unique challenges with care and adherence when compared to others.

**HIV** in the South: Important Factors to Consider. The South lags behind other geographic areas in the quality of care and prevention (CDC, 2016a), which demands attention if the HIV epidemic in the U.S. is to end.. The South, which includes 16 states and the District of Columbia, has the highest burden of HIV illness and death (CDC, 2016a). The epidemic within the South is unique in that there are higher diagnoses in suburban and rural areas when compared to other regions of the U.S. (Reif et al., 2015). It is important to note that the Deep South, which includes Alabama, Florida, Georgia, Lousiana, Mississippi, North Carolina, South Carolina, Tennessee, Texas, receives the least amount of federal funding overall in the US despite the heavy burden of HIV (Reif et al., 2017). Factors that contribute to HIV infection and disparities in this geographic region of the U.S. include poverty, racism, lack of access to healthcare, and stigma.

*Poverty*. In the South there are a number of economically disadvantaged communities, some of which have the highest burden of HIV among women (Breskin et al., 2017). More than a third of persons living in the South lived in poverty areas defined as a census tract with a poverty rate of 20% or more, where in other geographic areas 19-25% of the population lives in poverty stricken areas (Jeffries & Henny, 2019). Furthermore, the median household income in the South

has been consistently lower when compared to other geographic areas of the U.S.. To end the HIV epidemic in the U.S. and specifically in the South, the Southern HIV/AIDS Strategy Initiative suggests the need for more nuanced funding distribution in states where the HIV/AIDS epidemic does not follow the urban-centric national pattern (Southern AIDS Strategy, 2018).

*Racism.* Racial differences are also noted, where black women represent 57% of all HIV diagnoses among women in the South (CDC, 2019) (Centers for Disease Control and, 2019). Even though poverty is a known contributing factor to these disparities, research has consistently demonstrated an association between African American race and poorer healthcare access even after controlling for income and health insurance (Mays et al., 2007; Napravnik et al., 2006; Williams et al., 2016). Additional social determinants that could potentially explain the racial disparities in HIV diagnosis rates "include institutionalized racism, high sexually transmitted infection rates (STI), lack of trust in healthcare and the government, and higher rates of incarceration. These determinants have been shown to be negatively associated with sexual networks (Adimora et al., 2014, p. 848; Flom et al., 2001; Kalichman et al., 2016; Maulsby et al., 2014; Reif et al., 2017).

*Access.* There are also high rates of people without health insurance in the South. Georgia has reported that 14.9% of their residents are uninsured compared to 10% nationally (Kaiser Family Foundation, 2019a). Many Southern states have also opted out of Medicaid expansion that was available through the Affordable Care Act (Jeffries & Henny, 2019; Reif et al., 2017). Another issue is transportation to healthcare facilities. The South has many rural areas that limit the accessibility of healthcare and other social services.

*Stigma.* Significant cultural factors, such as homophobia, racism, and general discomfort discussing sexuality, contribute to stigma around HIV in the South (Valdiserri, 2002). This

stigma then negatively affects people's desire to be tested for HIV and receive care. "A qualitative study of HIV care infrastructure that included individuals living with HIV and individuals working in HIV prevention and care in the Deep South found that stigma was pervasive and reduced willingness to be tested for HIV, engage in HIV care, and participate in HIV support groups and advocacy efforts" (Reif et al., 2017, p. 849; Reif et al., 2016)." This finding is similar for other STIs, where for which there are also feelings of self-blame, guilt, and discrimination (UNAIDS, 2016). However, HIV-related stigma is often layered with other related stigmas, including sex work, substance abuse, poverty, and race (Reif et al., 2017). All of these factors contribute to the Southern HIV epidemic. These factors must be addressed and further studied to help WLWH, especially those who reside in the South.

### **Purpose of the Study**

Postpartum retention in care can go unnoticed in routine clinical practice since patients sometimes change insurance or clinical providers after delivery. Postpartum mortality can also go unnoticed as patients sometimes die years later without a designated clinical provider. Therefore, the challenges of retaining WLWH in care after delivery may not be well understood. The current research suggests that postpartum retention in care may be associated with health outcomes among postpartum WLWH. This study proposes to test the hypothesis that low retention in care is associated with poor HIV outcomes, such as viral suppression and mortality. As part of the initial model for testing postpartum retention in care and clinical outcomes, additional patient and socioeconomic factors that are known to contribute to health outcomes will be included. These contributing factors will help to develop a comprehensive model that incorporates the complex interaction of risk and protective factors for those with limited retention in care. The specific aims of this study will be addressed using a sample of WLWH who delivered a live infant post-enrollment into the Women's Interagency HIV Study. This is a national observation cohort of 4982 HIV-positive and high-risk HIV-negative women at 10 sites within the US and including four sites in the South.

Aim 1: Determine the time from date of last delivery to death for postpartum WLWH enrolled and delivered between 1994 and 2017.

Hypothesis 1 (H1): Women from the Southern sites will experience a shorter time to death post-delivery than women from non-Southern sites.

Aim 2: Determine the proportion of postpartum women (defined as any woman reporting a live birth post enrollment) that are retained in care (adaptively defined as at least two health care visits in a 12-month period) for each calendar year between 1994 and 2017 and whether retention is associated with viral suppression (< 200 copies/ml) for each year.

Hypothesis 2.1 (H2.1): Those considered to be retained in care (at least two health care visits in a 12-month period) will be more likely to be virally suppressed over time than those who are not.

Hypothesis 2.2 (H2.2): There will be a significant difference in the proportion of postpartum women who are retained in care and virally suppressed in the Southern sites and non-Southern sites; a smaller proportion of women in the Southern sites are retained in care and virally suppressed.

Aim 3: Examine the effects of the predisposing and enabling factors on health behavior (retention in care) and health outcomes (mortality and viral suppression) based on the Andersen Behavioral Model of Health Services Use (ABM).

Hypothesis 3 (H3): Low retention in care (not having at least two health care visits in a 12-month period) will be influenced by contextual (southern versus non-southern),

predisposing factors (age, race, marital status, education, income/employment, depression, and substance abuse) and enabling factors (social support, housing, and health insurance coverage) and associated with higher rates of mortality. The ABM assumes that predisposing and enabling factors are predictors for various health issues.

Women's Interagency HIV Study. The Women's Interagency HIV, established in 1993, is a multi-center, prospective, observational cohort study of women living in the U.S. who are either HIV-infected or at risk for HIV acquisition. The original Women's Interagency HIV Study sites are located in and around 6 cities in the US: Bronx, NY; Brooklyn, NY; Washington, DC; Los Angeles, CA; San Francisco, CA; and Chicago, IL. Four new southern sites were added to the study in 2013 including Chapel Hill, NC; Atlanta, GA; Miami, FL; and a shared cohort site between Birmingham, AL and Jackson, MS. "The core study visit includes a detailed and structured interview, physical and gynecologic examinations, and laboratory testing. Women's Interagency HIV Study plays an important role in NIAID's effort to understand the current epidemiology of HIV infection, disease progression, treatment use and outcomes, and related comorbidities among U.S. residents with HIV (National Institute of Allergy and Infectious Diseases, 2017)."

### Significance of Research

Although some studies have examined associated risks for health outcomes among WLWH, few studies have investigated the role of postpartum retention in care in important health outcomes such as mortality over a long period. This study will not only determine the time from a significant time point, such as delivery to death but also how well women are retained in care after birth of a child. This study is significant in that it will be determine if the time of delivery to death is related to retention in care after delivery. Research to fill the gaps in knowledge regarding the care continuum is a primary goal of the Health Resources and Services Administration (HRSA), and this study aims to have a direct impact on efforts to improve care and treatment for HIV-positive women in the U.S. (Health Resources Services and Administration, 2017). The Andersen behavioral model of health services use will serve as the guiding framework for this study.

This research contributes to the body of knowledge regarding the Andersen Behavioral Model of Health Services Use by examining retention in care as health service utilization in multiple HIV hotspots. The new and unique body of knowledge that was created from this study will expand the application of the Andersen model to other vulnerable populations, especially those experiencing socioeconomic health disparities.

### Andersen Behavioral Model of Health Services Use

A determining factor for the utilization of health services, such as being retained in care postpartum, are the health needs created by predisposing socioeconomic factors. Behavioral models take the view that, apart from health condition factors, health service utilization is influenced by an individual's economic, demographic and social circumstances (Babitsch et al., 2012). One model that appropriately frames health service utilization and thus postpartum retention in care is the Andersen Behavioral Model of Health Services Use.

The ABM is used to demonstrate that there are factors and conditions that impede or facilitate health service utilization. Health service utilization can be as simple as medical appointments or as complex as hospitalizations and home care. The model is used to assist in developing interventions to promote equal access to care (Andersen, 2008). The evolution of the model can be described in five phases. The original model (Phase 1) in the 1960s had an

emphasis on assisting and measuring dimensions of access to care. Phase 2 or the next iteration of the model (1970s) featured significant additions, including the physical healthcare system and adding consumer satisfaction. These measures were added in a separate overarching domain and included sub-concepts such as resources of the health care system that included volume and distribution. This change recognized the importance of these dimensions to health policy and health services use. The third phase (1980s-1990s) added more of an individual aspect by including personal health behaviors, such as diet and exercise. Health status as an outcome was included in the model, which recognizes that the purpose of the health system is to improve and maintain health. During this phase, most relationships are only influenced in one direction. The fourth phase (1990s) of the model shows the dynamic and recursive nature of health services use, and the feedback loops between the different domains, such as individual characteristics and the utilization of health care services. This change also opened the model to more challenging conceptualizations and experimental study designs. The fifth and current phase (2000s) of the model stresses contextual and individual factors as determinants of healthcare utilization. Contextual and individual characteristics are different in that the contextual characteristics are collected in aggregate, such as the demographic breakdown of a city in comparison to the individual self-identified demographics of one person. A model revision that reflects these changes in the 2000s is shown below (Figure 2).



This model includes three categories of factors that determine health services utilization: predisposing, enabling, and need factors (Andersen, 2008)(Andersen, 1995). Predisposing factors are defined as demographic characteristics, social structure, and health beliefs. Key demographic factors that have been identified as influential in health services utilization are gender and age. Social factors include occupation, drug use, education, ethnicity, and relationships such as marriage. These predisposing factors comprise part of the model that influences utilization.

The second part of the model involves enabling factors. Enabling factors are described as conditions that may be changed by an individual and social effort. For example, being pregnant or having health insurance are conditions that may be changed by individual effort according to this model. These are personal factors that may enable a person to use health services or prevent them from doing so.

The last part of the model involves need factors, which include evaluated and perceived needs. Perceived need is defined as the views and experiences of individuals regarding their health and whether their health status requires health services. In contrast, the evaluated need is described as the objective measurement or healthcare professional's assessment of whether an individual's health status requires health services. As HIV is a chronic lifelong condition requiring long-term care, it is both an evaluated and perceived need. Along with predisposing and enabling factors, need factors are the final element in determining the facilitation and impediment of health care service utilization, such as postpartum retention in care. To further understand the use of the Andersen behavioral model of health services use, previous applications of the model in relevant studies must be analyzed and critiqued.

Application of Andersen's Behavioral Model of Health Services Use. The Andersen behavioral model has been used to explore factors affecting key health outcomes among PLWH.

Investigators have used the model extensively in a variety of contexts and categorizations for predisposing and enabling factors (Holtzman, 2015). Babitsch and colleagues (2012) completed a systematic review of such studies that used the model (Babitsch et al., 2012). The 1995 version of the model (Phase 4) was the most frequently used. However, there were significant differences in the variables (or predisposing, enabling, and need factors) used. The majority of the studies included in the present review used age, marital status, gender/sex, education, and ethnicity as predisposing factors. In contrast, income/financial situation, health insurance, and usual source of health care were used as enabling factors. Concerning need factors, evaluated health status and self-report/perceived health were categorized into this domain in a wide variety of diseases. The major finding from this review was the lack of consistency in findings. The authors have hypothesized that the contexts of these studies had strong and unique impact on the strength, existence, and directions of the associations found in these studies.

Studies specific to HIV using the Andersen Behavioral Model of Health Services Use have included unique qualitative studies that examine barriers to health services for women and men living with HIV. Andrasik and colleagues (2008) examined barriers to cervical cancer screening among low-income HIV-positive African American women (Andrasik, Rose, Pereira, & Antoni, 2008). Their findings suggested the importance of psychological and emotional barriers in addition to the commonly reported socioeconomic barriers. Their application of the model helps to emphasize that all three subdomains — predisposing, enabling, and need factors — must be taken into account to understand health care utilization in WLWH.

One of the most useful studies to apply the Andersen Behavioral Model of Health Services Use to HIV care was a grounded theory study of HIV-positive adults in Philadelphia (Holtzman et al., 2015). The investigators sought to map out barriers to and facilitators of retention in care and antiretroviral therapy adherence using the Anderson model. A qualitative analysis of interview data from 51 persons living with HIV was analyzed for barriers and facilitators according to the Andersen behavioral model. The researchers found 11 common barriers to both retention in care and antiretroviral therapy adherence, including substance abuse. The major finding of the study was the utility of the Andersen Behavioral Model of Health Services Use as a framework for classifying factors influencing HIV-specific health behaviors.

In addition to specific health behaviors, contextual factors are an essential part of the Andersen Behavioral Model of Health Services Use. Few studies have examined contextual factors and patient characteristics using this model (Bossuyt et al., 2011; Fonseca, Antunes, Cascaes, & Bomfim, 2019; Hlebec, 2014; Imbus, Voils, & Funk, 2018; Kaskie et al., 2011; Rebelo Vieira, Rebelo, Martins, Gomes, & Vettore, 2019; Wilkinson, Glover, Probst, Cai, & Wigfall, 2015). Hawk and colleagues (2017) conducted a mixed-methods study examining contextual and health care environment factors in a Ryan White Program clinic that were associated with viral suppression. The investigators found that the 340B Drug Discount Program, a federal drug discount program that facilitates organizations to purchase medications at greatly discounted prices, enabled the clinic's ability to care for people infected with HIV (Hawk et al., 2017, p. 496). The study expanded the application of the Andersen Behavioral Model of Health Services Use by including the influence of the health care environment on health behavior.

However, the application of the Andersen Behavioral Model of Health Services Use has been sparse for WLWH, especially in the area of retention in care. Two studies have highlighted a need to focus on social-emotional components to increase health service use (Andrasik et al., 2008; Zulliger et al., 2015)Previous research from Andrasik and colleagues found that addressing psychological and emotional barriers is important in improving cervical cancer screening among low-income WLWH. Zulliger and colleagues (2015) determined that female sex workers who had a positive perception of HIV care providers were more likely to be retained in care. These studies did not minimize economic or healthcare system barriers and provided a holistic representation of how health service use can be improved within this vulnerable population. These and other studies validate the use of this model for the proposed study (Brennan et al., 2015; Conserve et al., 2017; Starbird et al., 2018).

**Key Constructs.** By using the ABM as a conceptual framework to understand postpartum retention in care following delivery among WLWH, this study identifies factors that are unique to women at a distinct life stage and with a distinct health status such as pregnancy. A diagram of the ABM used for this study is shown in Figure 3.





Critical constructs of the model used in the present study include:

*Contextual Environment.* The contextual environment for the proposed study is classified according to the Women's Interagency HIV Study site (Southern versus non-Southern) provided in abstraction forms for the study. The Southern sites are Chapel Hill, NC; Atlanta, GA; Miami, FL; and Birmingham, AL/Jackson, Mississippi. The non-Southern sites are Bronx, NY; Brooklyn, NY; Washington, DC; Los Angeles, CA; San Francisco, CA; and Chicago, IL.

*Patient Factors.* Patient factors include predisposing factors such as age, race, substance abuse, education, marital status, income/employment, and depression and enabling factors such as housing, social support, and health insurance coverage. Age and race are separated from the other factors because these are unchangeable or static factors that an individual cannot change on their own. – The others can change over a patient's lifetime. In terms of health insurance coverage, people in Medicaid expanded states are more likely to be eligible for the Medicaid coverage for those with annual incomes below 138 percent of the federal poverty level. This expansion has been shown to have implications not only for coverage, but also for access, affordability, and health outcomes (Guth et al., 2020). It also has positive economic effects, such as reduction in uninsured visits and care, and positive effects on employment and the labor market. All of the four Southern Women's Interagency HIV Study sites are located in states that have not expanded Medicaid, while the original study sites are located in states that have expanded Medicaid. The constant need factor within this population is positive HIV status, as it is a lifelong condition requiring continuous care and monitoring.

*Health Behavior.* The health behavior within the model for this study is retention in care. Retention in care for this study is defined as at least two healthcare visits within a 12-month period. *HIV Health Outcomes.* The HIV health outcomes included for the analysis include mortality and HIV viral load (greater or less than 200 copies/mL). The hypothesis is that retention in care after delivery for WLWH is associated with these outcomes, as shown in the above model, and may also be associated with contextual or patient factors.

The ABM provides an overview of factors that influence postpartum retention in care among WLWH. The models and associated studies help to form a baseline for understanding the many predisposing factors behind low retention and eventual mortality.

#### **Chapter 2: Background and Significance**

This chapter examines the factors surrounding HIV postpartum mortality and retention in care. It is organized into the following sections: (1) pregnancy and the postpartum period in women living with HIV (WLWH), including mortality rates; (2) HIV in the environmental context of the Southeastern United States; (3) patient factors related to mortality and retention in care; and (4) gaps in the literature that should be addressed in future research.

### Pregnancy and the Postpartum Period Among WLWH

More than 8,500 women living with HIV give birth annually in the United States (CDC, 2016). However, within this vulnerable population where care is linked to outcomes, only half of WLWH are considered to be retained in care, and of those retained, only 48% are virally suppressed. Furthermore, the stabilized mortality rate among WLWH is three times higher than that of uninfected women overall and ten times higher than that of women in a similar age group (French et al., 2009). When it comes to pregnancy-related death, WLWH have a risk of death nearly eight times higher than their uninfected counterparts (Clara Calvert & Carine Ronsmans, 2013). Although several factors are associated with these outcomes, the underlying causes remain elusive. This chapter will outline the physiological differences between WLWH and HIV-uninfected women and go on to discuss the differences between WLWH and men living with HIV.

WLWH and HIV-uninfected women. WLWH have key gynecological differences from HIV-uninfected women. These specifically concern cervical dysplasia (which can be a risk factor for developing cervical cancer) and response to treatment for cervical dysplasia. Although WLWH are not different from uninfected women in terms of morbidity or complications from cervical dysplasia, the prevalence and recurrence are higher in this population. In view of these high rates of recurrence, the importance of follow-up cannot be overestimated. Even with treatment, the risk of treatment failure for lesions is also higher among WLWH. In a metaanalysis and systematic review of studies published between 1980 and 2018 focusing on residual or recurrent precancerous lesions after treatment of cervical lesions among WLWH, Debeaudrap and colleagues (2019) found that the odds of treatment failure were nearly three times higher in HIV-infected women than in uninfected women (Debeaudrap et al., 2019). The increased risks associated with cervical dysplasia in this population in comparison to HIV-uninfected women underline the importance of appropriate follow-up and care for WLWH.

The interaction between HIV infection and pregnancy is not well understood. The current evidence suggests that pregnancy does not progress WLWH to HIV/AIDS-defining illness (Calvert & Ronsmans, 2015). Furthermore, HIV does not appear to increase the risk of direct obstetric complications other than intrauterine infections (C. Calvert & C. Ronsmans, 2013). Based on these findings, Calvert and colleagues suggested that reducing mortality in this population should not be focused on obstetric management but rather on interventions involving access to antiretroviral therapy (ART) in pregnant and nonpregnant WLWH (C. Calvert & C. Ronsmans, 2013). In other words, the eight-times-higher risk of pregnancy-related death among WLWH in comparison to HIV-uninfected women may not be improved simply by addressing intrauterine infections (C. Calvert & C. Ronsmans, 2013; Clara Calvert & Carine Ronsmans, 2013) This increased risk of pregnancy-related mortality has been found in multiple studies. Because antiretroviral therapy is the cornerstone of health management for WLWH, and, given the unique contribution of HIV to disease processes, proper care management, including retention in care, is crucial. Furthermore, unique HIV-care recommendations for WLWH are needed, not only to differentiate them from uninfected female adults but also to differentiate them from male HIV-infected adults.

WLWH and men living with HIV. The HIV epidemic in the United States disproportionately affects men who have sex with men, and the majority of new cases occur in this population (Kaiser Family Foundation, 2019b). However, WLWH have unique care needs in comparison to men living with HIV. Women have been found to have lower plasma viral loads and higher CD4 T-cell counts than men living with HIV, both of which are important markers of HIV disease status and progression (US Department of Health and Human Services, 2001). However, such advantages are lost over time. The reasons for this loss are unclear, but it may be the case that in low-resource settings, women have less education and less income than men do, thus hindering optimal HIV care (Hawkins et al., 2011). Women are also more likely to discontinue antiretroviral therapy than men, suggesting that women may respond differently or experience more side effects than men (Carrel & Willard, 2005; Currier et al., 2010; Libert et al., 2010). For example, while taking nevirapine which is often used in combination therapy, both men and women may experience a rash; however, the rash is more likely to be severe in women. Women are also more likely than men to experience changes in body composition due to lipodystrophy (Project Inform, 2003; Rehman & Nguyen, 2021).

Given such differences, the lack of research on women is disturbing. The dearth of female representation in HIV research contributes to severe knowledge and care gaps for this vulnerable population. Although women represent more than half of the adults worldwide living with HIV, they account for only 19% of clinical trial participants (Currier et al., 2010). The reasons for this lack of representation may include the potential for pregnancy, lack of childcare services, and lack of social support (Currier et al., 2010). Furthermore, "young women (aged 15 to 24) are TWICE as likely as young men to experience an HIV/AIDS-related illness in North America" (Meditz et al., 2011). These gaps, along with the misperception that women are at a lower risk of contracting HIV, can contribute to delays in HIV care and increased susceptibility to opportunistic infections (Gandhi et al., 2004; Moore et al., 2001). The numerous unique prevention challenges among women cannot be overestimated. These challenges include anatomical characteristics that make it easier to contract HIV, the fact that a current sexually transmitted infection (STI) increases risk more than it does in men, relative lack of control in relationships, and potential histories of trauma and sex abuse (Office on Women's Health, 2018). Research has successfully identified the amount of risk and the prevention challenges for different gender groups and sexual orientations; however, for women, and especially pregnant and postpartum women, these risks are not easily modifiable.

**Pregnancy and HIV.** Perinatal transmission has been significantly reduced with the advent of ART, but there are still shortcomings in HIV care for pregnant WLWH (CDC, 2016b). Factors that have been cited include (1) women living with HIV not knowing their serostatus; (2) women living with HIV not knowing they are pregnant, how to prevent or safely plan a pregnancy, or what they can do to reduce the risk of transmission; and (3) social and economic factors affecting access to healthcare. This is extremely disturbing, as maternal and pediatric health are closely linked.

Although pregnancy itself is not associated with HIV disease progression, research has suggested that increases in viral load occur in the early postpartum period (Sha et al., 2011; Tai et al., 2007). Decreased adherence to treatment following delivery has been identified as one possible contributing factor. Reasons this may include care for the newborn baby and the perception that the newborn child is not vulnerable to HIV (Mellins et al., 2008). However,
approximately 61% of women report perfect adherence to antiretroviral therapy during pregnancy, which leaves a sizable proportion non-adherent. There are few changes in medication, as the antiretroviral therapy is the same for non-pregnant and antepartum women (Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission, 2021). A change would only occur if a woman already on antiretroviral therapy were on medicines considered to be teratogenic: her regimen would be changed when pregnancy occurred or in the process of preconception planning. However, evidence is limited on the prevalence of these medication changes. In summary, the reasons for lower adherence in the postpartum period are complex and somewhat unknown. However, the evidence is clear there is a difference in adherence between the antepartum and postpartum period (Bardeguez et al., 2008; Mellins et al., 2008). The consequences of lack of retention include virologic resistance, mortality, and morbidity. Although a large number of studies have addressed the effects of retention in care on clinical outcomes in persons living with HIV in general, fewer have examined postpartum retention in care among WLWH in the United States, and even fewer have examined mortality in this population.

#### **Postpartum Mortality in WLWH**

Assessing the impact of low retention in care on mortality among WLWH is essential in developing the global knowledge base. The immediate post-birth period can be overwhelming, and to improve future outcomes, it is crucial that women stay in care and good health by taking their medicines during this critical time. Suboptimal postpartum adherence to antiretroviral therapy is linked to progression to AIDS and to increased morbidity and mortality up to 18–20 months postpartum (Landes et al., 2012). If antiretroviral therapy is interrupted in the period immediately following delivery, WLWH will progress more rapidly to AIDS (Kesho Bora Study)

et al., 2012). Additionally, antiretroviral therapy nonadherence has been shown to contribute to a four-times-higher risk for mortality (Aye et al., 2017). The CD4 (cluster of differentiation antigen 4 glycoprotein) count is an important laboratory test that shows how well a person is responding to HIV treatment and the level of disease progression. For WLWH with CD4 counts below 200 within 24 months postpartum, mortality has been found to be 54 times higher than in those with CD4 counts greater than 400 (Hargrove et al., 2010). This demonstrates that WLWH are a significant high-risk group in the first few years of the postpartum period.

Although there are unique factors that contribute to maternal mortality among WLWH, they have a higher risk of maternal mortality overall than women who are not infected with HIV (Hogan et al., 2010; Lozano et al., 2011). HIV is a contributing factor in 19,000 to 56,000 maternal deaths worldwide (Lozano et al., 2011), accounting for approximately 6% to 20% of maternal deaths globally (Lathrop et al., 2014). Furthermore, WLWH have a risk 2 to 10 times greater of dying during pregnancy and in the postpartum period compared to their uninfected counterparts (Clara Calvert & Carine Ronsmans, 2013; Le Coeur et al., 2005; Moran & Moodley, 2012; Van Dillen et al., 2006; Wandabwa et al., 2011).

Although many studies have examined mortality among WLWH, the resulting estimates may be faulty for a number of reasons. First, women who are physiologically capable of pregnancy may be healthier than women who cannot become pregnant (Hurt et al., 2006). Therefore, to estimate and compare the overall mortality of pregnant WLWH and nonpregnant WLWH, a rigorous adjustment must be made for disease stage; otherwise, pregnancy-related mortality will be underestimated. Furthermore, estimates may be diluted unless time-limited effects such as age, time period, and socioeconomic status are taken into consideration. As women age, they are more likely to die due to old age or increased exposure to chronic diseases. Depending on the time period, the structure of healthcare systems and contemporary care guidelines can influence the risk for mortality. For example, the current perinatal guidelines, updated in 2018, recommend that WLWH see an HIV-care provider within two to four weeks after delivery, a suggestion absent from the 2017 guidelines (HHS Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission—A Working Group of the Office of AIDS Research Advisory Council (OARAC), 2017). Therefore, women who become pregnant and deliver an infant in 2018 or later receive a different standard of care than women who became pregnant and delivered before 2018. This disparity may influence a woman's morbidity and mortality risk based on when she receives care and how much care she receives after delivery. Finally, changes in socioeconomic status in terms of a woman's education, training, family income, and a host of other factors can increase or decrease mortality risk.

Currently, the evidence base is limited regarding whether pregnancy is an independent factor associated with increased risk of death among WLWH. The few studies that have examined crude mortality rates among WLWH on antiretroviral therapy have shown mixed results. Moreover, the studies that reported no effect involved significant losses upon follow-up, which might have led to underestimations of maternal mortality (Westreich et al., 2013). In their large cohort study (n=918 of HIV-positive women) from Johannesburg, South Africa, Westreich and colleagues did not find pregnancy to be an independent factor for increased risk of death (Westreich et al., 2013). However, they cautioned their findings in the context they had very few deaths in their study (21 out of 918 women) and substantial amounts of missing data related to women dropping out or being loss to follow-up as evidenced by only 918 participants have one recognized pregnancy follow-up out of 7,534. Furthermore, they acknowledged if women were experiencing miscarriage (which is still a pregnancy exposure) and not reporting it - that

wouldn't have been as accurately captured in their data. Most of the recent research in this area has been conducted in low-resource settings and has included interventions to optimize Option B+, "a prevention of vertical transmission approach for expectant mothers living with HIV in which women are immediately offered treatment for life regardless of their cluster of differentiation 4 (CD4 count)," in various African countries (Clouse et al., 2014; Global Network of People Living with HIV, 2013; Katirayi et al., 2016; Nance et al., 2017).

**Option B+.** Option B+, developed and expanded by the World Health Organization, is the offering of ART to all pregnant and breastfeeding WLWH for life. The program primarily targets developing countries. It is a one-pill-a-day regimen, which makes it easier for women to adhere to their medication schedule (Division of Global HIV/AIDS [DGHA] of the CDC, 2012). The program began in 2013, and within a year of implementation the number of pregnant and breastfeeding WLWH on antiretroviral therapy had increased by more than 700% (Chimbwandira et al., 2013). The essential element of Option B+ is that lifelong antiretroviral therapy is started regardless of the stage of HIV infection. The decentralization of service delivery has facilitated increased access to care. The first country to adopt this approach was Malawi, and other countries have since joined, including Cameroon, the Democratic Republic of the Congo, the Dominican Republic, Ethiopia, Haiti, Kenya, Mozambique, Namibia, Rwanda, Tanzania, Uganda, and Zambia (Division of Global HIV/AIDS [DGHA] of the CDC, 2012). In the United States, medical experts have also updated guidelines for healthcare providers according to a committee review. These guidelines have implications for the care and well-being of WLWH.

**Renewed focus on the postpartum period.** As stated in Chapter 1, the American College of Obstetricians and Gynecologists (ACOG) recently made a significant change to its

recommendations for postpartum care. The organization had previously recommended that postpartum women receive a single, comprehensive visit within the first six weeks after giving birth. In a new Committee Opinion published in 2018, ACOG made the following recommendation: "All women should ideally have contact with a maternal care provider within the first three weeks postpartum. This initial assessment should be followed up with ongoing care as needed, concluding with a comprehensive postpartum visit no later than 12 weeks after birth (ACOG, 2018, p. 1)." Furthermore, in the United States, pregnancy-related complications (including complications that occur during the postpartum period) result in 700 deaths each year (ACOG, 2022). For every death, there are 70 severe maternal morbidity events which may result in significant short- or long-term consequences for a woman's health. These new policies and care standards are to confront the maternal mortality and morbidity crisis within the United States. This does not represent the full extent of U.S. policies on pregnancy and postpartum care for WLWH. The Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission of the Department of Health and Human Services has issued detailed guidelines for this population (Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission, 2018). Table 1 summarizes the key recommendations for postpartum follow-up of WLWH.

Table 1. Follow-Up Recommendations of the Panel on Treatment of HIV-Infected PregnantWomen and Prevention of Perinatal Transmission

Panel's Recommendations

Antiretroviral therapy (ART) is currently recommended for all individuals living with HIV to reduce the risk of disease progression and to prevent the sexual transmission of HIV (AI).
 Any plans for modifying ART after delivery should be made in consultation with the woman and her HIV care provider, ideally before delivery, taking into consideration the recommended regimens for nonpregnant adults (AIII).

• Because the immediate postpartum period poses unique challenges to antiretroviral (ARV) adherence, arrangements for new or continued supportive services should be made before hospital discharge (AII).

• Contraceptive counseling should start during the prenatal period; a contraceptive plan should be developed prior to hospital discharge (AIII).

• Women with a positive rapid HIV antibody test during labor require immediate linkage to HIV care and comprehensive follow-up, including confirmation of HIV infection (AII).

• Prior to hospital discharge, the woman should be given ARV medications for herself and her newborn to take at home (AIII).

• Breastfeeding is not recommended for women in the United States with confirmed or presumed HIV infection, because safer alternatives are available (AI).

• Infant feeding counseling, including a discussion of potential barriers to formula feeding, should begin during the prenatal period, and this information should be reviewed after delivery (AIII).

Rating of Recommendations: A = Strong; B = Moderate; C = Optional

Rating of Evidence:  $I = One \text{ or more randomized trials with clinical outcomes and/or validated laboratory endpoints; II = One or more well-designed, nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion$ 

This change in practice recommendations will have a significant impact on WLWH in terms of increasing the number of visits they have before transitioning to HIV care and improving the opportunities they have to address any issues that could hinder retention in care. In areas with high HIV burdens, especially the Southern United States, such approaches and guidelines will contribute to the creation of an AIDS-free generation.

#### **HIV in the Deep South**

Social factors, such as poverty and program characteristics, are considered significant determinants of retention in care among people living with HIV overall (Geng et al., 2010). This is most apparent in the Southeastern United States (otherwise known as the Deep South). The Deep South is traditionally considered to include South Carolina, Georgia, Alabama, Mississippi, and Louisiana. Some also consider Florida and Texas part of this geographical area due to their shared borders with the other five states (New World Encyclopedia, 2020). In the most recent

literature, the deep south has also included the states of the Tennessee and North Carolina. All these states share similar cultural contexts and history which influence HIV outcomes. In general, individuals in the South experience higher mortality rates from all causes compared to the general U.S. population, and these disparities are associated with socioeconomic factors (Murray et al., 2006). Unique policies and conservative politics fuel HIV infection in the South (Adimora, Ramirez, Schoenbach, & Cohen, 2014). First, the region is the poorest in the nation (Wimberly, 2010). People in this region are less likely to have health insurance, which contributes to health disparities (Mekouar, 2015).

Furthermore, the South scores low on access to care and on the quality of care provided to all patients. Geographically, many areas are suburban or rural, which requires patients to travel long distances for care. Like anywhere else in the United States, Medicaid is available to those who qualify. However, Medicaid income eligibility is more restrictive in the South, and the benefits are much lower in some states. Many Southern states contribute less than the national average to state AIDS assistance programs that would help people living with HIV initiate and maintain HIV care (Lefert et al., 2013). Other institutionalized restrictions, including outlawing sodomy, lack of syringe exchange programs, and refusal to expand Medicaid coverage, all contribute to the high rates of HIV infection seen in the South (Adimora, Ramirez, Schoenbach, & Cohen, 2014). These policies and structures contribute to poor access to HIV care and delays in the receipt of care, which have been identified as reasons for the lack of viral suppression in people living with HIV in the South (Bhatta et al., 2010).

As mentioned in Chapter 1, race also has an influence on the prevalence and outcomes within persons living with HIV. First, 42% of new HIV infections are in African American men and women, despite the fact that they only represent 13% of the U.S. population (CDC, 2020b).

This overrepresentation overlaps with other social determinants linked to racism within the South. For example, the South has some of the highest incarceration rates for African Americans, a factor known to increase the risk of HIV acquisition (Bailey et al., 2017). Furthermore, most Southern states focus on abstinence-only sex education. This means that young African Americans, who already experience heavy educational disparities, do not receive the necessary information to practice safe sex (Stillman, 2014). Finally, institutional structures that discriminate against African Americans, such as the 1935 Social Security Act, which excluded agricultural and domestic workers (positions mostly held by African Americans, explaining why Southern Democrats wanted this exclusion), have hampered the accumulation of intergenerational wealth and locked the bulk of this population into poverty. As a result, severe racial economic inequities persist to this day and have led to the spread of HIV, a disease considered to be a plague of poverty (Zinn, 2014). This provides a unique intersectional context for WLWH in the South.

Unique challenges and characteristics of WLWH in the South. Compared to the overall United States, the South has been found to have higher proportions of women infected with HIV (Reif et al., 2015). The HIV epidemic among women in the South is characterized by areas in which there is a predominance of heterosexually acquired infections, a larger impact on blacks, and a higher proportion of the population residing in rural areas than in urban areas (Fleming et al., 2006). This influence of the distinctive Southern context is evidenced by the differences in HIV-care outcomes and events. Meditz et al. (2011) found that people living with HIV in the South experienced significantly more HIV-related morbidity than their counterparts who lived in other regions. They also start antiretroviral therapy later than their counterparts in the Northern and Western United States (Meditz et al., 2011). This study also found that both

white and nonwhite women from the South experienced poorer outcomes than men. This shows the importance of including women in HIV research even though the overall number of infections in this population is decreasing.

In addition to the external physical environment and access to care, the social context also influences outcomes among WLWH. The social context in the South is unique and fuels HIV infection. This is demonstrated by the influence exerted by neighborhood characteristics, such as social disorders like violent crime rate, on sexual risk behaviors of WLWH (Haley, Haardörfer, et al., 2017). The conservatism of the South is another important influential factor for WLWH. In a qualitative study addressing stigma, one participant noted how secretive WLWH are about their status in the context of the "backwardness" of the Southern states in understanding and accepting people with HIV (Darlington & Hutson, 2017). This stigma in the South influences the social support available for WLWH from both their families and the healthcare system. Providers are critical in fighting the HIV/AIDS epidemic. In Felix et al.'s (2010) study of referral facilitation, nearly all family planning providers sampled facilitated prompt referrals, but the reasons cited for low facilitation included a perception of few referral resources and no personal relationships with referral providers (Felix et al., 2010). This highlights not only that WLWH require a strong social support network but also that providers should be connected across disciplines to provide prompt care. Unique challenges in the South that may need to be addressed in order to improve care include strengthening social support networks, such as relationships with healthcare providers (Buchberg et al., 2015). Because the South bears a substantial part of the burden of the HIV epidemic in the United States and has a higher proportion of women with HIV, it is crucial to examine predictors in this uniquely disadvantaged social context to improve outcomes for WLWH.

The Women's Interagency HIV Study (WIHS) has completed multiple investigations into unique phenomena among WLWH in the Southern sites. As mentioned in Chapter 1, the Women's Interagency HIV Study is a prospective cohort study observing the impact and progression of HIV among women in the United States (Bacon et al., 2005). In 2013, the investigators established and enrolled women from Southern sites, including Alabama, Florida, Georgia, Mississippi, and North Carolina. However, there are some limitations in the representativeness of this data; most sites are in cities and they do not necessarily capture a "Southern effect" or recruit women from rural areas. All in all, these sites are an important addition, because the South now bears a disproportionate part of the burden of the HIV epidemic.

Studies that have focused on Southern sites have found an association between neighborhood characteristics and sexual health factors, including high-risk behaviors and STIs (Haley, Haardörfer, et al., 2017; Haley, Kramer, et al., 2017). However, the most important of these Southern-focused studies examined factors associated with healthcare access. Greater neighborhood healthcare access was found to be associated with fewer sexually transmitted infections (Haley et al., 2018; Haley, Haardörfer, et al., 2017). This lays the groundwork for further studies of women living in the South that elucidate the barriers and facilitators for retention along the care continuum.

The National HIV/AIDS Strategy calls for a high level of retention in care and reduction of the death rate among persons living with HIV (USDHHS, 2017). Reaching these national benchmarks depends on increasing access to care and improving health outcomes for those living with HIV. This is supported by information and resources that strengthen the delivery of services along the care continuum, such as research that fills gaps in knowledge regarding specific subgroups at the state level (Office of National AIDS Policy, 2015). There is suboptimal retention and engagement of women in HIV care in the South (Oliver et al., 2019). Researching the factors associated with poor retention in care can help policymakers and stakeholders craft and direct the resources needed to improve postpartum retention in care for WLWH.

## Factors Associated with Poor Retention in Care

This section reviews studies that have examined (1) the influence of the contextual environment and (2) patient factors, including predisposing and enabling factors associated with postpartum retention in HIV care. Because much of the research on WLWH has been conducted in low-resource countries, the review includes studies conducted both within and outside the United States.

To better understand the factors associated with retention in HIV care following delivery, it is helpful to contextualize environmental and patient factors using a behavioral health model. The ABM (described above) provides a theoretical framework for understanding environmental and patient factors that influence health outcomes and behaviors (Andersen, 1995). These constructs can be grouped into three broad domains: environment, patient, and health behavior. Examples of environmental factors include the external environment, such as rural and urban areas. Examples of patient factors include predisposing factors, such as age, race, and gestational age. Also included among patient factors are enabling factors, such as multiple diseases or health processes and health insurance. The constant-need factor in our study is HIV status, which requires lifelong medication and monitoring by an HIV-care provider. Examples of relevant health behaviors include being retained in HIV care, both prenatally and in the postpartum period. An adaptation of this model, previously shown in Chapter 1 and reproduced again here in Figure 3, clarifies how factors in the external and patient domains can influence WLWH's health behaviors concerning retention in care.



*Figure 3*. Andersen Behavioral Model of Health Services Use for Postpartum Retention in Care and Mortality for WLWH.

**Predisposing factors.** To review, predisposing factors are characteristics intrinsic to the patient. These characteristics are not easily changeable, as reflected by the dashed line, but they do influence health behaviors such as retention in care. This study examines the intrinsic factors of age, race, substance use, depression, marital status, education, and income.

*Age*. Reproductive-age women are considered to be between 15 and 44 years of age, according to the CDC (CDC, 2017). Age has been found to be associated with various aspects of HIV care, including ART initiation, adherence, and retention. For the most part, younger women have been found to have an increased risk of not being retained in care in comparison to older

women (Ayuo et al., 2013; Giuliano et al., 2016; Kiwanuka et al., 2018; Knettel et al., 2018; Oliver et al., 2019; Orne-Gliemann et al., 2017)

Ayuo et al. (2013) found that as age increases, the odds of disengagement decrease. The researchers hypothesized that younger women may not appreciate the need or have the resources to follow up in care to the same extent as their older counterparts. HIV is not as much of a death sentence as it was in the past. Therefore, younger women may perceive that the condition is simple to manage by taking pills, and this perception limits the seriousness with which they take follow-up (Crook & Cavanaugh, 2011). In their systematic review of retention in HIV care, Knettel and colleagues (2018) found that women under the age of 25 typically had poor retention, while Orne-Gliemann and colleagues (2017) found that women older than 32 had better retention. However, it is important to note that overall, younger women are less likely to visit healthcare providers because they are healthier and experience fewer chronic diseases than older women (Siddiqui et al., 2014). This has important implications in terms of what is inferred from associations between age and poor retention.

Some studies have found that increasing age (or older age) is associated with poor retention in care among WLWH (Dzangare et al., 2016; Foster et al., 2017; Meade et al., 2019). For example, Kreitchmann et al. (2012) found that nonadherence increased with each one-year increase in age. The investigators hypothesized that these findings might be related to the higher demands of being an older WLWH, particularly a WLWH with young children (Kreitchmann et al., 2012). The differences in findings due to age and developmental stage underline the importance of targeted interventions.

*Race.* There is little evidence of a significant association between race and postpartum retention in care. Two studies have been carried out to examine this association, one in the

Southern state of Mississippi and one in the Northern state of Pennsylvania. In (Rana et al., 2010) study of Mississippian WLWH, they performed a retrospective chart review to determine the factors associated with optimal follow-up. One of these factors included if women presented for the first time when already in the third trimester they more likely to have less than optimal follow-up. These women were usually African American and younger; however, it should be noted that 89% of their overall sample was African American. Despite this prevalence, on multivariate and univariate analyses they did not find a significant association with race. The investigators in the Pennsylvania study also performed a retrospective review, looking at follow-up at 1 and 2 years postpartum (Adams et al., 2015). They found a small but significant odds ratio whereby African American women were more likely to be in care at 1 year postpartum than Caucasian women. However, this advantage was lost at the two-year retention mark. It appears, therefore, that although race plays an important factor in the access and quality of healthcare, other individual factors may be more important for postpartum retention.

*Substance use.* In addition to age, substance use, which includes the use of tobacco, alcohol, and illicit substances, is an important patient factor that influences HIV care. Illicit drug use strongly influences adherence and, consequently, retention in care. Even when women are not currently using substances, a history of drug use increases the risk of nonadherence to antiretroviral therapy and, as a result, loss to follow-up postpartum (Cohn et al., 2008). This is consistent with the results of a Swiss cohort study in which a history of injection drug use was associated with postpartum loss to follow-up (Aebi-Popp et al., 2016). Bardeguez et al. (2008) found that the odds of perfect prescribed medication adherence were significantly higher for women who had never used marijuana than for those who had. Alcohol and tobacco use have

also been identified as predictors of nonperfect adherence during pregnancy and the postpartum period (Kreitchmann et al., 2012).

In a systematic literature review of studies focusing on antiretroviral therapy initiation, adherence, and retention among pregnant and postpartum WLWH, Hodgson et al. (2014) found only two studies that focused on substance use. Bardeguez et al. (2008) found higher than expected rates of drug use in their sample, with the most frequently reported drugs being tobacco, marijuana, and cocaine. Both of these studies were conducted in the United States, demonstrating that, especially in the midst of the opioid epidemic, more research is necessary (National Institute on Drug Abuse, 2018). The extant research suggests that exploring current and past drug use is important for understanding retention in HIV care following delivery.

*Depression.* The impact of depression on the HIV care continuum among WLWH is not well understood. What is known about depression among WLWH is that they are disproportionately affected, that depressive symptoms are associated with disease progression, and that depression may contribute to poor maternal outcomes at delivery and postpartum (Evans et al., 2002; Goedhart et al., 2010; Morrison et al., 2002). Despite these poor outcomes, depression has not been found to be a strong predictor of retention (Momplaisir, Aaron, et al., 2018; Yotebieng et al., 2017). (Momplaisir, Aaron, et al., 2018) examined the influence of depression in a sample of Philadelphian WLWH across four continuum outcomes: viral suppression at delivery, care engagement, retention, and viral suppression at one year postpartum. The authors found that despite the high prevalence of depressive symptoms, intensive case management services may mitigate the risk for poor continuum outcomes. This has important implications for WLWH who have depressive symptoms, but more research needs to be done across different contextual environments in the United States.

*Marital status, education, and income.* Research has not produced as many significant or relevant retention-in-care results regarding the predisposing factors of marital status, education, and income. (Oliver et al., 2019) examined substance use and demographic and socioeconomic factors in a cohort of Southern women. They found that married women were less likely to have poor viral suppression (i.e., less likely to have a high viral load), but that marriage did not affect retention in care. In contrast, they found that lower educational attainment was associated with poor retention but not with poor viral suppression. They postulated that "women may differ in characteristics that affect their ability to adhere to medical appointments but not their ability to adhere to medications and vice versa" (Oliver et al., 2019, p. 6). For example, a woman's lack of reliable transportation does not impair her ability to adhere to antiretroviral therapy. Other studies have not found similar results regarding marital status (Yotebieng, Thirumurthy, Moracco, Edmonds, et al., 2016; Yotebieng, Thirumurthy, Moracco, Kawende, et al., 2016). In regard to education, the literature is broadly consistent with Oliver and colleagues' study, finding that lower educational attainment is associated with higher odds of loss to follow-up (Giuliano et al., 2016; Kiwanuka et al., 2018; Oliver et al., 2019). Giuliano and colleagues highlighted the importance of peer-to-peer education programs in targeting women of lower socioeconomic status (and most likely lower educational attainment) as a way to improve retention for this vulnerable population. Although these studies indirectly touched on or measured income, few studies have found significant associations with income level, especially when it comes to postpartum retention in care.

**Enabling factors.** Enabling factors are those that support a patient's use of healthcare. Common enabling factors for postpartum WLWH include healthcare, social support, housing, and health insurance.

*Social support.* Previous studies have shown that a lack of social support among HIVinfected individuals is associated with higher levels of perceived stigma, lack of HIV/AIDS disclosure, higher levels of depressive symptoms, and, most disappointingly, greater reluctance to seek care (Galvan et al., 2008; Moneyham et al., 2005; Vyavaharkar et al., 2010; Vyavaharkar et al., 2011). The quantitative and qualitative results of (Buchberg et al., 2015) study, which assessed facilitators of and barriers to retention, indicated that a lack of interpersonal social support outside the immediate family, feelings of internalized stigma, and high levels of depressive symptoms were associated with poor retention in care. Women reported disclosing HIV/AIDS only to immediate family members because of past experiences of stigma. The investigators hypothesized that this lack of disclosure limited their support network and therefore exacerbated their feelings of competing responsibilities. In other words, because their support network consisted only of family members, WLWH had to take on multiple responsibilities themselves instead of delegating those responsibilities to others. Similarly, Clouse et al. (2018) and Kiwanuka et al. (2018) found that disclosure was closely linked to social support and retention in care. However, even with social support, some patients experience treatment interruptions (Tabatabai et al., 2014). Strategies that help patients overcome modifiable barriers are essential.

*Housing.* There is limited evidence regarding the influence of housing on retention in care in the uniquely vulnerable population of WLWH. Based on the work of Holtzman et al. (2015), it is known that in the general HIV population, housing has a stronger influence on adherence (ability to consistently take medications) than retention (attending appointment visits) (Holtzman et al., 2015). In their qualitative study mapping out patient-identified facilitators of and barriers to retention in care, Holtzman and colleagues (2015) found that participants reported

privacy and security concerns related to taking medication in an unstable housing setting. For example, participants with unstable housing feared stigma and worried about their medications being lost or stolen. These concerns were related to lacking a secure place to store medications. Furthermore, without a stable address, some participants were unable to complete the paperwork required to maintain health insurance. For people in these troubling circumstances, adhering to medications and keeping appointments became less important.

*Health insurance coverage.* There is limited evidence regarding the influence of health insurance on postpartum retention in care. This may be because most pregnant WLWH are eligible for Medicaid during pregnancy, and in expanded states all members in a household are covered if the income is below a certain level (U.S. Centers for Medicare & Medicaid Services, 2020). Health insurance is therefore usually not a barrier during the prenatal period; however, it may become an issue in the postpartum period if the only eligibility criterion a woman living with HIV meets is current pregnancy. Furthermore, other predisposing and enabling factors may contribute more strongly to optimal retention than health insurance. Overall, health insurance coverage was found to be associated with appropriate maternal healthcare utilization (Achia & Mageto, 2015; Kibusi et al., 2018; Were et al., 2020). Were and colleagues (2020) examined pregnant Kenyan women living with HIV and found that social health insurance coverage increased the likelihood of improved obstetric healthcare utilization, including greater access to institutional delivery and skilled birth attendance. However, these results may not translate to the postpartum period, especially in a high-resource setting such as the United States that does not have universal health insurance.

In summary, the factors that influence the postpartum retention in care of WLWH fall into two categories: contextual and patient factors. One key contextual factor is living in a Southern versus a non-Southern environment: Southern women experience unique barriers, such as a lack of access to care and social norms that hinder retention. Furthermore, institutional disparities fuel the HIV epidemic in Southern regions. Conservative social norms regarding sex and drug use instigate and exacerbate the stigma around HIV in this region, which can make disclosure and access to care difficult.

A host of patient factors, including younger age, lack of education and income, and substance use, increase the risk of poor retention. These factors are interdependent. Research that identifies significant factors, such as age, and factors with mixed findings, such as depression, is needed to improve the HIV care continuum in this population.

### Gaps in the Literature

Consistent retention of women in care after delivery is important because it is predictive of future engagement in care and mortality. WLWH should consistently follow up after delivery to allow healthcare providers to check for changes in viral status and the efficacy of ART. The literature has identified a variety of factors that are predictive of loss to follow-up. The factors associated with mortality are similar to those associated with poor retention; they include poor medication adherence, other predisposing factors, and drug use. Overall, according to the few studies conducted in the United States, retention in care is low for WLWH following delivery. Most of these studies have been conducted in low-resource settings. If studies were done in the United States, they were not necessarily based in the sociocultural context of the South, Abstinence-based sex education and criminalization of HIV-related risk behaviors have resulted in increased stigma and discrimination (Sangaramoorthy & Richardson, 2017). Furthermore, in the wide literature WLWH have higher rates of mortality from direct maternal causes with a 5.2 times rate of direct maternal mortality in comparison to women who do not have HIV (Clara

Calvert & Carine Ronsmans, 2013). Hence, there is a knowledge gap concerning the scope of the problem and the understanding of these factors in a population of Southern WLWH.

In summary, there are serious gaps in the knowledge base regarding women living with HIV due to physical and social determinants. These gaps hinder the care and diagnosis of WLWH and may lead to poor health outcomes. Studies such as this one will expand the knowledge base and demonstrate the importance of postpartum retention in care for the lifespan of WLWH. This study elucidates the factors that increase the risk of mortality and loss to followup care in this population after giving birth.

#### **Chapter 3: Methods**

This chapter presents the methods used to address the aims of this research and test pertinent hypotheses. Study specifics are presented in the following sections: overview, research design, setting and sample, instrumentation and materials, outcome measures, data management, data analysis, ethical considerations.

#### **Overview**

This study used the Andersen Behavioral Model of Health Care Utilization, to evaluate factors associated with mortality and retention in care among women living with HIV (WLWH) enrolled in a large prospective cohort from the Women's Interagency HIV Study (WIHS). The purpose of this study was to identify mortality rates among postpartum WLWH along with predictors of retention in care in the years following delivery of previously diagnosed WLWH with live births post enrollment. Women who delivered a live infant during the study period (1994–2017) are eligible for inclusion in the study.

Retention in care after delivery (defined as two health care visits in a 12-month period) and time until mortality were the primary dependent variables. Other social determinants, such as age, race, marital status, education, income/employment, depression, substance use, social support, housing, and health insurance coverage (including whether respondents had Medicaid expanded health insurance) were examined as predictors of retention in care and mortality. The statistical methods used to determine the relationships between the variables include the Kaplan-Meier method (time to event being from date of delivery to death), logistic regression for examining the important variables of retention in care (two healthcare visits in a 12-month period) and viral suppression (< 200 copies), simple logistic regression for viral suppression, and multivariate Cox regression analysis to build a model that predicted time until death controlling for retention and other covariates.

#### Aims and Hypotheses

Quantitative research questions and hypotheses were used to frame and complete this research. The specific aims of this study were addressed using a sample of WWH who delivered a live infant during enrollment in the WIHS. The WIHS includes a national observation cohort of 4,982 HIV-positive (HIV+) and high-risk HIV-negative (HIV-) women at 10 sites in the United States, including four sites in the southern region of the country. The following aims and hypotheses were explored in the this study:

Aim 1: Determine the time from date of last delivery to death for postpartum WLWH enrolled and delivered between 1994 and 2017.

Hypothesis 1 (H1): Women from the Southern sites will experience a shorter time to death post-delivery than women from non-Southern sites.

Aim 2: Determine the proportion of postpartum women (defined as any woman reporting a live birth post enrollment) that are retained in care (adaptively defined as at least two health care visits in a 12-month period) for each calendar year between 1994 and 2017 and whether retention is associated with viral suppression (< 200 copies/ml) for each year.

Hypothesis 2.1 (H2.1): Those considered to be retained in care (at least two health care visits in a 12-month period) will be more likely to be virally suppressed over time than those who are not.

Hypothesis 2.2 (H2.2): There will be a significant difference in the proportion of postpartum women who are retained in care and virally suppressed in the Southern sites and non-Southern sites; a smaller proportion of women in the Southern sites are retained in care and virally suppressed.

Aim 3: Examine the effects of the predisposing and enabling factors on health behavior (retention in care) and health outcomes (mortality and viral suppression) based on the Andersen Behavioral Model of Health Services Use.

Hypothesis 3 (H3): Low retention in care (not having at least two health care visits in a 12-month period) will be influenced by contextual (southern versus non-southern), predisposing factors (age, race, marital status, education, income/employment, depression, and substance

+use) and enabling factors (social support, housing, and health insurance coverage) and associated with higher rates of mortality. The ABM assumes that predisposing and enabling factors are predictors for various health issues.

A retrospective longitudinal design was chosen because only secondary data was available from the WIHS dataset, and no data or specimen collection was performed as part of this analysis. The WIHS national coordinators provided individual-level data from the WIHS dataset, which was used for both descriptive and multivariate data analysis.

# **Setting and Sample**

The population for this study is comprised of WLWH in the United States who were of reproductive age at the time of their enrollment in the WIHS. As noted above, there are currently about 4,982 women participating in the WIHS—3,702 HIV+ (74%) at last visit and 1,280 (26%) high-risk HIV- women at last visit (Adimora et al., 2018). The median age of the WIHS sample is 49 years, which is within the reproductive age range of 15 to 49 years as defined by the United Nations Population Fund (UNFPA) (Adimora et al., 2018; Population Division Department of Economic and Social Affairs (DESA) & United Nations Population Fund (UNFPA), 2020). The WIHS cohort is representative of the population of WLWH who are in or out of care in their geographical region. The recruitment techniques used by the WIHS national team to ensure a

representative cohort includes face-to-face consultations with medical providers in multiple disciplines (such as infectious disease, internal medicine, and obstetrics/gynecology offices), outreach to HIV community organizations, churches, and ministries, and by word of mouth of existing participants (Bacon et al., 2005).

Given that the mortality rate of the sample was expected to be 10%, at least 300–500 subjects were needed to ensure a sample size of 30–50 individuals with that endpoint (i.e., mortality). With these parameters, the study was powered at 80% with a 5% level of significance to detect odds ratios between 1.55 and 1.77 (small-to-moderate effect sizes estimated by G\*Power) for each of the stated aims and endpoints, such as survival time, for all women experiencing mortality within the sample (Faul et al., 2013). An odds ratio of 1.77 is roughly equivalent to a Cohen's d=0.315, which is a small-to-moderate effect size and an odds ratio of 1.55 is equivalent to Cohen's d=0.242 which is a small effect size (Lenhard & Lenhard, 2016). The initial sample consisted of women with HIV who became pregnant while enrolled in the WIHS and for whom follow-up data is available.

Out of the initial sample of 306 women, six participants were eliminated because all their visits occurred before their last delivery. In other words, they gave birth post-enrollment but did not have any visits after their last delivery to extract data from. This brought the sample size down to 300. Thirteen (4.24%) participants had no retention data whatsoever and two participants (0.6% - one of which was also a participant with no retention data) had no viral load data. Removing these 14 participants brought down the sample size to 286. Finally, three additional participants were eliminated due to not having any predictor data over the entire study period – which gave the final sample size of 283. Eight participants specifically did not have any data/visits in their first year postpartum; however, they did have follow-up data and remained in

the study. Out of an eligible 306 women the final sample included 283 subjects including 42 subjects who died. Since this is slightly smaller than the original estimated size of 300-500, the expected effect size is small for the odds ratio of approximately 1.6 with 80% power, 5% level of significance with a sample size of 283.

Figure 4. Flowchart of women enrolled in the Women's Interagency HIV Study (WIHS) since 1994, illustrating the inclusion criteria for participants



# **Instrumentation and Materials**

This project used existing data from the WIHS along with the supplemental sources used in that study to track outcomes, such as the national databases used to track mortality rates. Secondary data analysis was advantageous because of the availability of existing surveillance and the ability to look at trends over time. The WIHS currently has sites in 10 cities in the United States, including Bronx, NY; Brooklyn, NY; Washington, DC; Los Angeles, CA; San Francisco, CA; and Chicago, IL. Four Southern sites were added to the study in 2013: Chapel Hill, NC; Atlanta, GA; Miami, FL; and a shared site within Birmingham, AL and Jackson, MS.

The WIHS methodology has been described extensively in other publications (Adimora et al., 2018; Bacon et al., 2005). In biannual study visits participants complete an interview with study personnel, undergo a clinical examination, and have laboratory specimens collected. Table 3 described the measures used including their time of collection. The measures that are the focus of this study are the predisposing and enabling factors in the pregnancy and postpartum period that can influence health outcomes such as retention and mortality.

#### **Outcome Measures**

The retention in HIV care for each eligible participant was determined based on the information available within the dataset based on the visit number. The WIHS participants completed a biannual visit where they filled out forms with the study staff. Although WIHS has been ongoing for over 20 years, not all questions have been consistently asked during the course of this large longitudinal cohort study. Thus, the variables available were different based on the visit number. The participants were classified as "retained in care" if they had two health care visits in a 12-month period following delivery. This is an adaptive definition for retention that is similar to the Institute of Medicine's parameters (HRSA, 2017; Rebeiro et al., 2014). Specifically, participants' responses to questions on health care utilization and specialized HIV care, as recorded in the WIHS dataset, were used to measure evidence of retention over time. These questions were not asked in visits 29–38 for all sites; for those visits, the undetectable viral load levels (< 200 copies/ml) were used as a proxy for retention. Viral load lab tests were collected during every participant visit. For comparative purposes, the analysis did not include examination of viral suppression as a proxy for retention for the other visits as that would be an important separate health outcome analysis in comparison to retention. Retention was examined within a certain span of study visits over time (i.e., visits 1–28, visits 29–38, visits 38–44, visits 45–49). A segmented approach was used within analysis, which helped to mitigate the strong time effects within such a long study. Table 2 shows how retention was measured over the study visits.

# Table 2

Measuring Retention Over Study Visits

X – question was asked within study visits

# $\square$ – surrogate measure for retention for visits 29–38

Question	Visits	Visits	Visits	Visits
	1–28	29–	39–	45–
		38	44	49
Have you seen your health care provider since (MONTH)	Х	-	Х	Х
visit?				
HIV care questions:	-	-	Х	Х
Participant has missed a regular HIV care appt. in past 6				
months				
Number of times participant received regular HIV care in				
past 6 months				
Number of times participant missed regular HIV care in past				
6 months				
Participant has received regular HIV care in past 6 months				
Frequency of participant's HCP requests if she receives				
regular HIV care				
Participant has received regular HIV care				
Viral suppression (< 200 copies)	-	V	-	-

Mortality was extracted from the core outcome forms and categorized by report of death (yes/no), cause of death, and date of death. Date of delivery/birth of the participants child was extracted from sociodemographic and obstetrical/gynecologic history questionnaires.

# **Independent Variables**

The variables that were extracted from WIHS include:

- Contextual Factors including the site of where the participant participated in the interview and whether this site was in a Southern-defined state. These sites include Bronx, NY, Brooklyn, NY, Washington DC, Los Angeles, CA, San Francisco, CA, Chicago, IL, Chapel Hill, NC, Atlanta, GA, Miami, FL, Birmingham, AL, and Jackson, MS.
- Predisposing factors, such as age, race, marital status, education, income/employment, depression, and substance abuse.
  - Age was recorded at visit time in number of years.
  - Race included American Indian or Alaskan Native, Asian, Native
     Hawaiian or Pacific Islander, Black/African American, White, Other, or
     Multi-racial.
  - Marital status included legally/common-law married, not married but living with partner, widowed, divorced/annulled, separated, never married, or other.
  - Education included no schooling, grades 1-6, grades 7-11, completed high school, some college, completed 4 years of college, and attend/completed graduate school.
  - Income included the average household income/year which was \$6000 or less, \$6000-\$12000, \$12001-\$18000, \$24000-\$30000, \$3000-\$36000,

\$36001-\$75000, or greater than \$75000. Type of income was also recorded including wages, welfare, social security/disability, other income, and multiple income sources.

- Depression score from the Center of Epidemiologic Studies Depression scale ranging from 0 to 60, with scores 16 or greater indicating risk of clinical depression (Lewinsohn et al., 1997).
- Substance abuse that was answered over multiple questions on whether a
  participant had use marijuana, cocaine, hash, etc. Alcohol use was also
  identified in whether a participant was an abstainer, or they did drink
  alcohol.
- Enabling factors, including social support, housing, and health insurance coverage, were also extracted.
  - Social support including whether in the past month participant was able to get help from family/friends, family/friends gave encouragement or understood worries.
  - Housing including whether participant was in their own house/apartment, parent's house, someone else's house/apartment, rooming/boarding/halfway house, shelter/welfare hotel, street, jail/correctional facility, residential drug/alcohol treatment facility, or other place.
  - Health insurance coverage whether the participant confirmed or denied having insurance in the first year postpartum of their last delivery.

Table 3 shows the attributes and time of collection of all predictors.

# Table 3

Predictors, Attributes, and Time of Collection

Predictor	Attributes	Time of Collection
Age	Age at visit	Screening/baseline
Race	American Indian or Alaskan	Screening/baseline
	Native	
	Asian	
	Native Hawaiian or Pacific	
	Islander	
	Black/African American	
	White	
	Other	
	Multi-racial	
Marital Status	Legally/common-law married	Collected over
	Not married but living with	multiple visits
	partner	
	Widowed	
	Divorced/annulled	
	Separated	
	Never married	
	Other	

Education	No schooling	Baseline and collected
	Grades 1-6	over multiple visits
	Grades 7-11	
	Completed high school	
	Some college	
	Completed 4 years of college	
	Attend/completed graduate	
	school.	
Income	\$6000 or less	Collected over
	\$6000-\$12000	multiple visits
	\$12001-\$18000	
	\$18000-\$24000	
	\$24000-\$30000	
	\$3000-\$36000	
	\$36001-\$75000	
	greater than \$75000	
Depression	Score ranging from 0 to 60,	Collected over
	with scores 16 or greater	multiple visits
	indicating at risk for clinical	
	depression.	
Alcohol Use	Abstainer	Baseline and over
	Non-abstainer	multiple visits

Substance Use	Yes	Baseline and over	
	No	multiple visits	
Social Support	Answered as a yes/no	Collected over	
	question on whether	multiple visits	
	participant got help from		
	family/friends, family/friends		
	gave encouragement or		
	understood worries.		
Housing	Own house/apartment	Collected over	
	Parent's house	multiple visits	
	Someone else's		
	house/apartment		
	Rooming/boarding/halfway		
	house		
	Shelter/welfare hotel		
	Street, jail/correctional		
	facility		
	Residential drug/alcohol		
	treatment facility		
	Other place.		
Insurance	Answered as yes/no on	Answered over	
	whether participant has	multiple visits but response	
	insurance coverage	used within study was the	

first year postpartum of the
last delivery

# **Data Management**

The use of each WIHS variable was subject to approval by the WIHS working group which adheres to very strict data management protocols. A concept sheet was submitted on June 18, 2020. This concept sheet was approved on July 24, 2020. Once this proposal was approved by the dissertation committee, the relevant WIHS data was compiled into a dataset for the primary investigator. The data was reviewed for missing values. The missing data and associated patterns were explored to establish whether data was missing at random. By reviewing the amount of missing data for each of the ten predictor variables (age, race, marital status, education, income/employment, depression, substance abuse, social support, housing, and health insurance coverage) by site (Bronx, NY; Brooklyn, NY; Washington, DC; Los Angeles, CA; San Francisco, CA; Chicago, IL; Chapel Hill, NC; Atlanta, GA; Miami, FL; and a shared site within Birmingham, AL and Jackson, MS) and visit number (visits 1–49), patterns of missingness within the data were approximated. These patterns included participants not following up and then reengaging; changes in health insurance coverage, especially after the 2014 implementation of the Affordable Care Act; and changes to the WIHS sites, such as the Los Angeles site closure in 2013 and the establishment of the Southern sites in that same year. The percentage of the sample that had missing data for the retention variables was determined. For each variable, the number of how many participants had missing data in the first year postpartum was determined. Multiple predictors had greater than 3 categories of responses allowed as seen in Table 3. This created very small groups of participants with said attribute (for example only three participants out of the 200 participants identified they were incarcerated). Therefore, for data analysis purposes, the predictors were collapsed into binary variables. For example, marital status was dichotomized as married and other than married, education was dichotomized as less than high

school and above high school education, income was dichotomized as having an income of \$18,000 or less and \$18,001 or more, depression was dichotomized was as depressed and not depressed, and housing was dichotomized as own house/apartment and other housing. To determine what predictor attribute to assign to a participant the proportion of responses for each category were determined. For example, married could hold a value of 1=married, 2=not married but living with partner, 3=widowed, 4=divorced/annulled, 5=separated, 6= never married, 7=other. 49.6% of participants reported they were married or not married but living with partner. This meant that 50.4% of the remaining responses were the other categories of widowed (1.1%), divorced/annulled (7.2%), separated (5.8%), never married (28.1%), other (2.2%), and missing/no response (6.1%). Therefore, due to the small numbers in the other categories and the majority of responses represented not being in a relationship, these remaining responses were collapsed into an "other than married" relationship status. Similar methodology was performed for education, income, depression, and insurance. For education, 39.9% of the responses were less than a high school education (1 = no schooling, 2 = grades 1-6, grades 7-11)and 50.4% were at or above a high school education (4=completed high school, 5=some college, 6=complete 4 years of college, 7=completed/attended graduate school).

In regard to income 59.7% of the participants reported an income of \$18,000 or less (1=\$6,000 or less, 2=\$6,001-\$12,000, 3=\$12,001-\$18,000) and 40.3% reported an income of more than \$18,000 (4=\$18,001-\$24,000, 5=\$24,001-\$30,000, 6=\$30,001-\$36,000, 7=\$36,001-\$75,000, and 8= more than \$75,000). 9% of the sample had missing data for income. With a majority of the participants reporting an income of less than \$18,000 those who had missing responses were collapsed into the new category of reporting an income of less than \$18,000 (values 1-3). Those who had responses indicating an income of greater than \$18,000 (values 4-8)

were categorized as such. In other words, the income responses were dichotomized into \$18,000 or less and over \$18,000 based on the proportion of responses observed. The numerical average for depression (11) was below the diagnostic threshold of 16, which for missing data was substituted for zero to reflect not only that the data was missing but most likely responses would not meet criteria for depression. Furthermore 61.7% of participants had a depression score of less than 16 indicating that a majority of the sample were not at risk for clinical depression. In regards to place of residence 79.9% of respondents reported they had their own house/apartment (1=own house/apartment) while 20.1% had other housing (2=parent's house, 3=someone else's house/apartment, 4= rooming/boarding/halfway house, shelter/welfare hotel, 6=street, 7=jail/correctional facility, 8= residential drug/alcohol treatment facility, 9=other place and missing). The missing responses were considered to most likely indicate unstable housing and were collapsed into other housing category (responses 2-9). This created a binary variable where place of residence was then coded as own house/apartment and other housing. Lastly when it came to insurance, 89.6% reported having insurance while 6.5% reported they did not have insurance. 11 participants had missing insurance data. A new insurance category was created where the missing datapoints were collapsed into the no reported insurance category. The proportions of missing data on these variables ranged from 7% - 17% and were not the main outcome of the study. Due to the longevity of WIHS, there were multiple questions asked over time on types of income such as wages, social security, etc. (20 original variables), substance use (12 original variables), and social support (3 original variables). The amount of missingness in these variables is due to a lack of a response where the participant most likely did not answer the question based on visit number. In other words, for types of income, substance use, and social support these questions changed or were asked later in the study and therefore appeared as
multiple variables asking the same question. WIHS is a vertically prepared dataset so for these variables some participants would be coded as having a missing response because they were not enrolled at the time and could not have answered the question. For example, if a participant presented for visit 9, the wage source questions they answered would be specific for visits 9-21 and not for visits 1-7. So, they would have a missing response on the wage source questions for visits 1-7, not because they didn't respond, but because the questionnaire has changed over time or they weren't even enrolled in the study at that time. For this reason, alternative measures were used for these covariates. Each of these three variables (source of income, substance use, and social support), were collapsed into one variable based on the person's enrollment/visit number and first postpartum year. Type of income was coded as wages, welfare, social security/disability, other income, multiple income sources, no reported Income Source. Drug and alcohol use were coded as yes/no substance use. And social support was coded as yes/no.

#### **Data Analysis**

All analyses were performed using SAS 9.4 (SAS Institute Inc, Cary, NC). To address the first aim, which sought to determine the time from delivery (based on the most consistent last live birth date of delivery) to death (for women experiencing mortality), the survival time for each participant who died was determined. Since a positive skew is often seen with long follow-up times, medians are used (50% percentile) as a better indicator of average survival time than means. In other words, because follow-up times are usually longer, by using the median there is a better capture of the average than using a mean (UCLA Institution for Digital Research and Education Statistical Consulting, 2021). The median survival time is calculated by SAS as the smallest survival time for which the survivor function, as in the probability that a participant will survive beyond the study period, is less than or equal to 0.5 (Brookmeyer & Crowley, 1982). Estimates were obtained of the mean survival time by default using the SAS PROC LIFETEST

procedure; however, the median was unable to be determined by the 50<sup>th</sup> percentile within the survivor function estimates within the output. These percentiles are representative of the cumulative hazard function where the expected number/proportion of failures (deaths) over the time interval. The upper quartile (25<sup>th</sup> percentile), however, was able to be obtained within the survivor estimates where 25% of the population was expected to have died. Subjects who died, were not counted as "at risk" i.e., they were considered "censored" and were not counted in the denominator (Goel et al., 2010). Right censoring was used in this study where this study had a fixed end time point of 2017 and did not follow participants till the end of their lifespans just the end of the study period or death. To address the first hypothesis (H1) that sought to determine whether Southern women have a shorter time to death, the STRATA statement was used to request that SAS compare survival of women in the Southern sites to those in the non-Southern sites by computing a Kaplan-Meier estimate to give a nonparametric estimation. Similar analyses were performed for the predisposing and enabling factors related to the other aims as appropriate.

To accomplish the second aim, the proportion of postpartum WLWH who were retained in care for each postpartum year was determined. To do this, the date of last delivery was examined to one/two/three year(s) postpartum rather than just the calendar year. Women who had a live birth during 1994–2017 were included in this analysis. As stated previously, retention in care was defined as at least two healthcare visits in a 12-month period. A variable was created for all women where they would be coded "yes" (they were retained in care for that postpartum year) or "no" (they were not retained in care for the postpartum year). The same was done for viral suppression (< 200 copies/ml); therefore, "yes" means they were virally suppressed for the calendar year, and "no" means they were unsuppressed for the calendar year. As mentioned

earlier, for visits 29-38 viral load was used as a proxy for retention since no specific healthcare utilization questions were asked during that period. For visits 39-49, specific HIV care questions were asked. However, for analysis purposes only the general healthcare provider question was used. Rationale for this was confirmed by using the kappa correlation coefficient comparing two modified variables: (1) retention using the general health care provider question and viral suppression for visits 29–38 and (2) retention using the general health care provider question for visits 1–28, viral suppression for visits 29–38, and specific HIV care questions for visits 39–49. The kappa coefficient was found to be .919, suggesting a high level of agreement between these two measures. The first measure of the general health care provider question was used to determine the proportion of women that were retained and virally suppressed, not retained and virally suppressed, retained and unsuppressed, and neither retained nor virally suppressed over time for each postpartum year. Those women whose 1, 5<sup>th</sup>, and 10<sup>th</sup> postpartum year that fell between visits 29-38 were excluded from these analyses (37 participants excluded in the 1<sup>st</sup> year, 76 excluded in the 5<sup>th</sup> year, and 68 excluded in the tenth year). The odds ratios were determined for retention and viral suppression using logistic regression. Large odds ratios resulted when there were too few cases within some categories to reliably estimate the statistical parameters. When this occurred only descriptive results were included for clinical understanding. For comparative and analysis purposes, categories of those who are not retained and virally suppressed, retained and unsuppressed, and neither retained nor virally suppressed were collapsed into one category for both descriptive and statistical estimates. The odds ratios/statistical estimates where there are too few cases to reliably estimate the statistical parameters were not reported. This resulted in really wide confidence intervals which are the result of unreliable estimates due to small numbers in the data (i.e., being from Southern site or

not having insurance). In other words, when the models were detecting a large odds ratio, the results were not reported (Cohen, 2013). In addition to predisposing and enabling factors, comparisons were made based on one-pill antiretroviral therapy era since advancements in treatment and care guidelines could influence the likelihood of being virally suppressed or retained. The last delivery year was used and if the year was 2006 and later this was categorized as post one-pill ART era and before 2006 (2005 and earlier) as pre-one-pill ART era. In other words, Hypothesis 2.1 (H2.1) was tested which posits that women retained in care are more likely to be virally suppressed.

An aggregate measure of retention and viral suppression was created for each participant. This was a proportion composed of the number of postpartum patient-years in which the retention-in-care criterion was met divided by the total number of postpartum years comprising the time interval. For example, a patient who delivered in 2005 would be evaluated from 2005 (post-delivery date) to 2017; if she was retained in care in 2006 and 2010, her proportion would be 16% (Figure 5).

Figure 5. Example of Aggregate Measure Re
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Year of	Last Year of	How many	How many	Years	Aggregate
Delivery	Study Period (2017 for those alive and year of death for	years retention in care criterion was met?	years total from last delivery?	Retained/Years Postpartum	Proportion
	those deceased)				
2005	2017	2	12	2/12	16%

This analysis was run including those with missing data where missingness was coded as not being retained or was unknown. Unknown was assigned to those responses where participants had a response that was other than yes, no, or missing from the original data. Ultimately in creating the aggregate measure these unknown responses were considered to be not retained in care.

A longitudinal logistic regression was then performed to examine the association of the predisposing and enabling factors with retention. With longitudinal logistic regression, repeated measurements of retention were examined on the same individuals over time. This method can determine what the likelihood of retention was over time for each participant by the factors of interest (Liang & Zeger, 1986). A generalized estimating equations approach was used in order to model the average response. In other words, the goal was to make inferences about the sample when accounting for within subject correlation. This approach allowed the production of regression estimates when analyzing a repeating measure such as retention which was examined at multiple time points. An attempt was made to examine the differences between Southern and non-Southern sites using multinomial logistic regression and bivariate chi-square statistics. Sites that were coded as Southern include Chapel Hill, NC; Atlanta, GA; Miami, FL; and a shared cohort site between Birmingham, AL and Jackson, MS. All other sites (Bronx, NY; Brooklyn, NY; Washington, DC; Los Angeles, CA; San Francisco, CA; and Chicago, IL) were coded as non-Southern. However, the Southern sample was too small (11 participants) to make meaningful inferences. Using the aggregate measure, Fisher's exact tests were performed to see if there was a significant statistical difference between these two types of sites. Multinomial logistical regression was used to compare the retention and viral suppression behaviors in the Southern and non-Southern sites. These analyses together attempted to answer Hypothesis 2.2 (H2.2) which posits that a smaller proportion of women are retained in care and virally suppressed in the Southern sites.

To accomplish the third aim, the aforementioned retention measures were used to create a Kaplan-Meier curve to determine whether the women who were retained in care after their most recent delivery had a better survival prognosis (time to death) than those who were not. A log-rank test was used to determine if there is a significant difference between the survival curves. A longevity retention in care measure was used. Postpartum retention in care was conceptualized up to the first care interruption (e.g., one year retained before care interruption, two years retained before care interruption, and three years retained before care interruption). The survival probabilities of retention in care were stratified by the predisposing and enabling variables to be consistent with the Andersen Behavioral Model. These survival probabilities were estimated using the Kaplan-Meier method. As mentioned earlier, right censoring was used in this study where this study had a fixed end time point of 2017 and did not follow participants till the end of their lifespans just the end of the study period or death. The log-rank test was used to compare probability estimates of retention in care between the survival curves.

Cox proportional hazards regression was performed to evaluate the variables (as age, race, marital status, education, income/employment, depression, substance abuse, social support, housing, and health insurance coverage) that predict poor retention, such as a categorical variable where participants did not meet the retention criterion (i.e., they did not have at least two visits in a 12-month period). The hazard ratio (HR) in the Cox regression model estimates the relative likelihood of poor retention at consecutive points in time after delivery. Evaluations were made using demographic and psychosocial predictor variables. Geographic variables were not run as stated earlier as the Southern states sample was too small to make meaningful inferences. As noted above, the predisposing factors include age, race, marital status, education, income/employment, depression, and substance abuse while the enabling factors include social

support, housing, and health insurance coverage. Predictor variables with a *p*-value < 0.2 were identified in univariate Cox regression analyses. In other words, variables included in the final model were chosen initially based on theoretical importance. However to avoid model overfitting with too many variables included, purposeful variable selection methods such as those described in Hosmer & Lemeshow (2013) were employed for variables where tests yielded smaller p-values < 0.2 (Hosmer Jr et al., 2013). Then, a multivariate Cox regression model was built using significant predictors and the measure of median retention proportion. This answered Hypothesis 3 (H3) which posits that predisposing and enabling factors are predictive of retention in care and mortality. The Schoenfeld residual tests were used to check the proportional hazards assumption for significant continuous variables.

#### **Ethical Considerations**

Informed consent was obtained after IRB approval by all participating WIHS institutions that conducted the research with WIHS participants. The WIHS concept form for this project was approved by the Atlanta site investigators and submitted to the national working group on June 18, 2020. This concept sheet was approved by the national working group on July 26<sup>th</sup>, 2020. Measures to maintain the confidentiality and integrity of the data include the deidentification of all data. In addition, the statistical procedures and analyses were conducted in a secure network environment at Emory University. While reviewing the dataset and conducting the analyses, a close collaboration with the WIHS Atlanta site investigators was maintained, specifically the principal investigator Dr. Anadi Sheth and the statistician Dr. Christine Mehta.

## **Difficulties and Limitations**

This study has multiple limitations. The first major limitation is the number of women from the Southern sites. The sample is too small to make any meaningful interpretations, especially for Aim 1. In terms of overall generalizability, participants reflect only those women who actively engaged in a research protocol and thus may not be representative of the general population of HIV positive women.

Another major limitation is the large amount of missing data for study visits 29–38 because the questions on the health care utilization form were not asked during those visits. Data was missing at random for variables where the questions did not change over time while for variables such as income type and substance use those questions changed over time. This challenge was mitigated by maintaining the consistency of the measures used to define retention and recording it as a pass/fail event for that postpartum year; if participants did not meet the criterion to be considered retained in care for a certain visit, such as not answering or being available to answer the health care provider's questions, or if they were unsuppressed, then they would not be considered retained in care at all for that study visit. Table 2 displays the variables used to measure, as best as possible, retention over time. The analysis was segmented and mapped out appropriately based on the aims and the available data corresponding to the visit number. Retention was used as a categorical variable rather than a continuous variable.

Another limitation is that the pregnancy data is in month/year format only. Women report their current and previous pregnancy data during each biannual visit, which can make it quite unclear when a pregnancy occurred. The pregnancy data also includes miscarriage, so if a woman was pregnant multiple times with multiples losses, this can make the data quite unclear. Therefore, the focus was on live birth data only, which was reported in month and year format. This limitation was managed by working closely with the senior biostatistician of the national WIHS team to prepare a succinct dataset of livebirth data only and used the 15<sup>th</sup> of the month as a placeholder date for deliveries. When examining retention from year to year, the responses were examined exactly 365 days from the last delivery date to be as specific as possible. Most importantly, a proxy definition for retention was used to examine women who reported a live birth post enrollment from the beginning of the study. This proxy definition(s) is outlined in Table 2, where viral load suppression was used as a surrogate measure for retention for visits 29–38. During these visits, the health care utilization questionnaire did not include questions on whether the participant had seen their health care provider since their last visit. The rationale for using viral suppression is that this reflects constancy with HIV medication and, most likely, health care. In addition, even with specific HIV care questions in later visits (visits 39–49), these HIV care questions ask whether the participant missed or received regular HIV care in the past six months but not the specific dates of HIV care. Therefore, depending on the date of a study visit, this may or may not be within the same postpartum year. In summary, the specific dates of health care utilization of the participants in WIHS cannot be determined despite the information provided by the healthcare utilization questions that are general throughout the study and specific to HIV care recently. However, an approximate measure of retention was found within this sample of women with adaptive measures.

This study was also limited in its capacity to capture a truly rural effect among the Southern states as most of the sites are located in urban areas and there is no explicit or implicit variable to determine whether the women are from rural areas. This will limit the generalizability of the study, not only nationally but also in terms of the ability to make inferences on the differences between the Southern and non-Southern sites. Not being able to capture a rural effect within the South is important because there are 35 persistently poor nonmetro (otherwise) counties within the United States and the South is home to 64% of these counties (Beachler et al., 2003). There is some recent geocoding with census tract data being collected for individual WIHS sites. But this variable is limited in availability. Furthermore, women from the Southern sites have shorter follow-up times as those sites were added in 2013, while the other sites have been in operation since 1994. This also has an influence on findings of mortality. In other words, women from the Southern sites do not necessarily have as long of a follow-up time to death in comparison to the original sites that have been in operation for more than 20 years.

Lastly, it is possible to not definitively determine the last live birth for women who have dropped out of the study. However, mortality was assessed for all active and inactive participants in the WIHS. This information is supplemented with information from the National Death Index

Despite these challenges, this rich dataset was used to not only to add to the national knowledge base but also gain insight into how postpartum retention in care is associated with mortality in a high-resource setting, such as the United States.

#### **Chapter 4: Results**

This chapter presents the results of the data analyses used to answer the research aims outlined in the previous chapters: (1) the time from the date of last delivery to death for postpartum women living with HIV (WLWH); (2) the proportion of postpartum women (defined as any woman reporting a live birth post-enrollment) retained in care (adaptively defined as at least two healthcare visits in a 12-month period) for each calendar year between 1994 and 2017, and whether retention was associated with viral suppression (< 200 copies/ml) for each year; and (3) the effects of the predisposing and enabling factors on health behavior (i.e., retention in care) and health outcomes (i.e., mortality and viral suppression) based on the Andersen Behavioral Model of Health Services Use.

The contents of this chapter are organized in the following sections. First, the general participant demographic characteristics are reported, including the proportion of postpartum intervals (number of years from last delivery to present/death). Second, survivor function estimates are given, including the median survival, to answer the first aim. Third, the results of chi-square and logistic regression are reported to address the second aim, which examines the data using the following categories: those who are retained and virally suppressed, those retained but unsuppressed, those not retained but virally suppressed, and those neither retained nor virally suppressed. Finally, the survival probabilities and Cox regression models are outlined to address the third aim.

#### **General Participant Demographics**

A total of 306 HIV+ women met the eligibility criteria for the analysis examining study participants from the beginning of the WIHS study in 1997 to 2017. A total of 398 live births

were identified. While 230 participants reported one live birth (75.2%), 76 participants reported more than one live birth (24.8%).

As stated earlier, after determining the last delivery date and the mortality status of all the participants, six participants were excluded because their last delivery date fell outside the study window. An additional 14 participants were eliminated because they had no retention or viral load data whatsoever. A final three participants were eliminated because they had no information on covariates, leaving 283 participants in the final sample. The descriptive findings are written in full below and summarized in the following tables. Table 4 summarizes the number of participants and proportion retained in the 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> postpartum year. Table 5 summarizes both continuous and categorical demographic characteristics within the sample, including retention.

### **General Characteristics**

Participants in the sample were predominantly, non-Southern (96.1%), were a race other than White (91.5%), had more than a high school education (59.0%), made \$18,000 or less a year (69.3%), reported not having any social support (65.4%), were not depressed (76.3%), had no history of substance use (85.2%), abstained from alcohol (69.3%), had some form of insurance (89.1%), and lived in their own house/apartment (78.5%). Over 15% of the sample died during the study period. Individuals were between 20 and 46 years of age. Sixty-two percent of the sample was retained in care the first year after delivery, however this dropped to approximately 47% of those participants alive and enrolled in the study 10 years after delivery (Table 4). Of note, women who were enrolled in WIHS longer and delivered earlier tended to have longer periods of follow-up for all measures. There was a significant difference found in those retained and not retained in the first (38.1% not retained versus 61.9% retained, pvalue=<.0001) and fifth postpartum year (58.8% not retained versus 41.2% retained, p-value=0.0072) but not in the tenth year postpartum (53.2% not retained versus 46.8% retained, p-value=0.4263) (Table 4).

#### **Postpartum Interval**

The time between the last delivery date and the endpoint (either the participant's death or 2017, ranged from less than a year to more than 23 years. The proportion of each participant's postpartum interval for which they were retained ranged from 0 to 100%. For the entire sample the median retained proportion was approximately 41%. Significant differences were determined between those who had above or below this median proportion by the predictors of interest (Table 5). Significant differences were found in education (p-value=0.02836), last delivery year by antiretroviral therapy (ART) era (p-value=0.0435), and housing (p-value=0.0170). No significant differences were found in all other predictors (p-value >0.05). Those with an education high school and above were more likely to have a retention proportion above 41%. Fifty-three point nine percent (53.9%) of participants with an education of high school and above (90 out of 167 participants) had retention proportion above the median compared to 47.4% of participants with education grade 11 or below (55 out of 116 participants). Participants who had their own house/apartment were more likely to have a retention proportion above 41%. 55% of participants who had their own house/apartment (122 out of 222 participants) had a retention proportion above the median compared to 37.0% of participants who reported other housing (23 out of 61 participants). Participants who delivered their child post-one pill antiretroviral therapy (2006 and later) were more likely to have a retention proportion above 41%. Fifty-nine point one percent (59.1%) of those who delivered their child 2006 and later (62 out of 105

participants) had a retention proportion above the median compared to 46.6% of participants who delivered their last child before 2006 (83 out of 178 participants).

# Table 4

Retention within  $1^{st}$ ,  $5^{th}$ , and  $10^{th}$  Year Postpartum since Last Delivery), n = 278

Retention Year	N of Participants	Not Retained	Retained	Chi-Square Test statistic (p- value)
		N (%)	N (%)	·
1 <sup>st</sup> Year	278	106 (38.1%)	172 (61.9%)	15.6691
_				(<.0001)
5 <sup>th</sup> Year	233	137 (58.8%)	96 (41.2%)	7.2146 (0.0072)
10 <sup>th</sup> Year	158	84 (53.2%)	74 (46.8%)	0.6329 (0.4263)

# Participant Demographics and Retention, n=283

			Total		
	Rete	ntion	(n=283)		
-	≤41% (Median	>41% (Median		Chi Square Test	Chi-
	Proportion	Proportion		Statistic	square/Fisher's
Measure in 1 <sup>st</sup> Year Postpartum	Retention)	Retention)			p-value
N	138	145	283		
Age $[M(SD)]$	32.54(5.0)	33.93 (5.4)	33.3 (5.3)		-
Race				0.0901	0.7640
White	11 (8.0%)	13 (9.0%)	24 (8.5%)		
Other	127 (92.0%)	132 (91.0%)	259 (91.5%)		
Site				-	0.0612
Non-Southern Site	136 (98.6%)	136 (93.8%)	272 (96.1%)		
Southern Site	2 (1.5%)	9 (6.2%)	11 (3.9%)		
Marital Status				0.2912	0.5895
Other Relationship Status	72 (52.2%)	71 (49.0%)	143 (50.5%)		
Married	66 (47.8%)	74 (51.0%)	140 (49.5%)		

Education				1.1499	0.02836
High School and Above	77 (55.8%)	90 (62.1%)	167 (59.0%)		
Grade 11 or less	61 (44.2%)	55 (38.0%)	116 (41.0%)		
Income Levels				0.1347	0.7136
> \$18,001/yr	41 (29.7%)	46 (31.7%)	87 (30.7%)		
≤\$18,000/yr	97 (70.3%)	99 (68.3%)	196 (69.3%)		
Income Type				-	0.6173
No Reported Income Source	89 (64.5%)	102 (70.3%)	191 (67.5%)		
Wages	14 (10.1%)	8(5.5%)	22 (7.8%)		
Welfare	10 (7.3%)	12 (8.3%)	22 (7.8%)		
Social Security/Disability	3(2.2%)	5(3.5%)	8 (2.8%)		
Other Income	2 (1.4%)	1 (0.7%)	3 (1.1%)		
Multiple Income Sources	20 (14.5%)	17 (11.7%)	37 (13.1%)		
Depression (CES-D) [M (SD)]	8.6 (11.1)	11.4 (11.7)	10.0 (11.5)		
				2.51756	0.1126
Not Depressed (score <16)	111 (80.4%)	105 (72.3%)	216 (76.3%)		
Depressed (score ≥16)	27 (19.6%)	40 (27.6%)	67(23.7%)		

Substance Use				0.6886	0.4067
No History of Substance use	120 (87.0%)	121 (83.5%)	241 (85.2%)		
History of Substance use	18 (13.0%)	24 (16.5%)	42 (14.8%)		
Alcohol Use				2.7413	0.0978
Abstaining	102 (73.9%)	94 (64.8%)	196 (69.3%)		
Not Abstaining	36 (26.1%)	51 (35.1%)	87 (30.7%)		
Insurance				2.1866	0.1392
No Reported Insurance	19 (13.8%)	12 (8.3%)	31 (11.0%)		
Reported Insurance	119 (86.2%)	133 (91.7%)	252 (89.1%)		
Social Support				2.0930	0.1480
No	96 (69.5%)	89 (61.4%)	185 (65.4%)		
Yes	42 (30.4%)	56 (38.6%)	98 (34.6%)		
Housing				5.6990	0.0170
Other Housing	38 (27.5%)	23 (15.9%)	61 (21.6%)		
Own House/Apartment	100 (72.5%)	122 (84.1%)	222 (78.5%)		

Era				4.0764	0.0435
Pre-One Pill ART (2005	95 (68.8%)	83 (57.2%)	178 (62.9%)		
and earlier)					
Post-One Pill ART (2006-	43 (31.2%)	62 (42.8%)	105 (37.1%)		
2017)					
Deaths that Occurred					
Postpartum during Study				0.2453	0.6204
Period					
Alive	119 (86.2%)	122 (84.1%)	241 (85.2%)		
Mortality	19 (13.8%)	23 (15.9%)	42 (14.9%)		
Deaths by ART Era				-	0.4682
Pre-One Pill ART (2005	6 (31.6%)	4 (17.4%)	10 (23.8%)		
and earlier)					
Post-One Pill ART (2006-	13 (68.4%)	19 (82.6%)	32 (76.2%)		
2017)					

#### Aim 1 Results

The following section presents an analysis of survivor function estimates and findings related to Aim 1, which sought to determine the time from the date of last delivery to death for postpartum WLWH.

#### Survivor Function Estimates

The breakdown of mortality between Southern and non-Southern sites can be found in Table 6. As stated earlier, the cumulative hazard function is the expected number of failures (in this study deaths) over the time interval (23 years). The mean survival time (follow-up time for those who are alive) in this study was 15.1 years postpartum of the last delivery. About 25% of the population was expected to die after 15.38 years (14.9% of the sample died). The median survival time was unable to be calculated because 50% of the sample did not expire. The average (as in raw time to death and not based on a survival curve) time to death, for those who died was 10.1 years. In other words, over the 23-year study period the expected rate of at least 25% mortality was not seen, suggesting the risk of mortality was low in the sample despite a shorter first quartile survival time of 15.38 years. These results may be related to right censoring, where participants leave the study before death occurs, or because this study did not follow all participants till the end of their lifespans just the study period end date of 2017. Table 6 presents the percentage of deaths at Southern and non-Southern sites.

Southern

 
 Site
 N of Participants
 Alive N (%)
 Deceased N (%)

 Non-Southern
 272
 230 (84.6%)
 42 (15.4%)

*Mortality by Study Site*, *n*=283

11

There were fewer participants from the Southern sites, and none of them died during the study period. This is reasonable because the southern sites have been operational since 2013 and therefore only having 4 years of possible follow-up. Hence, survivor function estimates were not performed based on these sites. Instead, survivor function estimates were performed on the covariates according to a non-parametric estimation. Table 7 presents the results of the continuous covariates where the parameter estimate is the percent increase and/or decrease in hazard ratio by factor increment (such as with each year in age or each discrete point score higher on CESD), Table 8 presents the results of the categorical covariates, and Table 9 presents the results of the significant categorical covariates.

11 (100.0%)

0 (0.0%)

Purposeful variable selection was used to examine the significant covariates of age, income, and substance use according to Cox regression and parametric model estimation (Hosmer Jr et al., 2013). There is a significant increase (6% as evidenced by the parameter estimate) in the hazard rate (hazard ratio = 1.071) for each additional year of age. However, this is to be expected, as the older a participant the more likely they are to die related to old age or other conditions (p-value=0.0233). Those with an income of less than or equal to \$18,000 in the first year postpartum had 3.296 times the risk of death when compared to those with an income higher than \$18,000 in the first year postpartum (p-value=.0123). Those who had a history of substance use in the first year postpartum had 3.565 times the risk of death when compared to those who had a history of the set who did not (p-value=<.0001).

Andersen Behavioral Model	Factor	Wald Test Statistic	<i>p</i> -value	Hazard Ratio	Parameter Estimate	Confidence Intervals
Predisposing Factor	Age	5.1432	.0233	1.071	0.06850	1.009, 1.136
Predisposing Factor	Depression	2.5386	.1111	1.018	0.01787	0.996, 1.041

Tests of Equality in Continuous Covariates for the Outcome of Mortality

# Table 8

Test Statistics and p-values of Tests of Equality in Categorical Covariates for the Outcome of

# Mortality

Andersen	Factor	Log-Rank	Wilcoxon	-2Log LR
Behavioral		Equality over	Equality Over	Equality Over
Model		Strata $X(p)$	Strata $X(p)$	Strata X(p)
Predisposing	Race (White vs.	1.69 (0.1931)	2.28 (0.1406)	2.63 (0.1047)
Factor	Other)			
	Marital Status	1.09 (.2972)	1.77 (.1836)	0.99 (.3200)
	Education	0.42 (.5153)	1.00 (.3181)	0.45 (.5009)
	Income*	7.05 (.0079)	8.88 (.0029)	8.30 (.0040)
	Substance use*	18.67 (<.0001)	9.63 (.0019)	14.89 (.0001)
	Alcohol Use	0.05 (.8212)	0.02 (.8769)	0.16 (0.6934)
Enabling Factor	Social Support	0.84 (.3582)	1.46 (.2272)	2.08 (.1496)
-	Housing	0.81 (.3677)	0.91 (.3404)	1.01 (.3145)
	Health Insurance	0.87 (.3523)	0.30 (.5858)	0.80 (.3715)
	Coverage			

\*Covariates with three significant tests of equality.

Factor	Parameter Estimate	Hazard Ratio	p-value
Income (Less than or equal to \$18,000 vs. More than \$18,000)	1.19262	3.296	0.0123
Substance use (History of Substance use versus No History of Substance use)	1.27126	3.565	<0.0001

Parameter Estimates and Hazard Ratios in Significant Categorical Covariates

## Aim 2 Results

The following section presents the results and analyses related to Aim 2 that sought to determine the proportion of postpartum women (defined as any woman reporting a live birth post enrollment) that are retained in care (adaptively defined as at least two health care visits in a 12-month period) for each calendar year between 1994 and 2017 and whether retention is associated with viral suppression (< 200 copies/ml) for each year. The hypotheses related to these questions include:

Hypothesis 2.1 (H2.1): Those considered to be retained in care (at least two health care visits in a 12-month period) will be more likely to be virally suppressed over time than those who are not.

Hypothesis 2.2 (H2.2): There will be a significant difference in the proportion of postpartum women who are retained in care and virally suppressed in the Southern sites and non-Southern sites; a smaller proportion of women in the Southern sites are retained in care and virally suppressed.

#### Hypothesis 2.1: Retention and Viral Suppression

This section presents the proportion of participants who were retained and/or virally suppressed. Earlier, Table 4 presented retention over time in the sample. Table 10 below presents viral suppression over time in the sample. As shown in Table 10, the majority of the participants were not suppressed at 1 (70.5%), 5 (76.0%), and 10 (68.4%) years postpartum.

#### Table 10

Viral Suppression in 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> Year Postpartum

Retention Year	N of Participants	Unsuppressed	Virally
			Suppressed
		N (%)	N (%)
1 <sup>st</sup> Year	278	196 (70.5%)	82 (29.5%)
5 <sup>th</sup> Year	233	177 (76.0%)	56 (24.0%)
10 <sup>th</sup> Year	158	108 (68.4%)	50 (31.7%)

Table 11 presents retention and viral suppression over time in the sample. In this table,

four categories of retention/viral suppression are described and the proportion of the sample that falls into those categories is displayed.

## Table 11

Retention and Viral Suppression in 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> Year Postpartum, n=241

Retention Year	N of Participants	Retained and Virally Suppressed	Retained and unsuppressed	Not Retained and Virally Suppressed	Not Retained and Unsuppressed
		N (%)	N (%)	N (%)	N (%)
1 <sup>st</sup> Year 5 <sup>th</sup> Year 10 <sup>th</sup> Year	241 157 90	60 (24.5%) 25 (15.9%) 22 (24.4%)	96 (39.8%) 51 (32.5%) 27 (30.0%)	6 (2.5%) 11 (7.0%) 3 (3.3%)	79 (32.8%) 70 (44.6%) 38 (42.2%)

Almost a third of the participants were not retained and unsuppressed in the first year (Table 11). Most notably, the category of retained/virally suppressed contained less than a

quarter of the participants. Despite having an extended follow-up time of 10 years, the proportion of participants retained and virally suppressed did not increase.

Because of the small numbers in the not retained/virally suppressed category and for ease of analysis and interpretation, the four categories were condensed into two: *Optimal outcome* (Retained and virally suppressed) and *Suboptimal outcome* (all others). Table 12 presents retention and viral suppression over time in the sample by these two categories.

#### Table 12

Retention Year	N of Participants	Optimal Outcome	Suboptimal Outcome
Ical	Farticipants	(Retained and	Outcome
		Virally	
		Suppressed	
		N (%)	N (%)
1 <sup>st</sup> Year	241	60 (24.5%)	181 (75.1%)
5 <sup>th</sup> Year	157	25 (15.9%)	132 (84.1%)
10 <sup>th</sup> Year	90	22 (24.4%)	68 (75.6%)

Retention and Viral Suppression in 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> Year Postpartum, n=241

These data show that the majority of the sample had suboptimal outcomes in each of the 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> postpartum years.

Next, Table 13 presents the proportions of retention and viral suppression for the first postpartum year by the predictors from the Anderson Model. The results of the first postpartum year are presented to make comparisons to the wider literature that commonly reports the first postpartum year or 12 months postpartum. Significant differences were found in the groups for the predictors of insurance, social support, and housing (p-value<.05). All other predictors (race, marital status, education, income, substance use, and depression) were found to not have significant differences between their groups (p-value >.05).

<u>Retention and Viral S</u> Covariate		Suboptimal	Total N (%)	<u>1=241</u> Chi-	Chi-
Covariate	Optimal Outcome (Retained and Virally Suppressed) N%	Outcome N%	10tai in (76)	Square Test Statistic	Square/Fi sher's p- value $X^1 =$ Fisher's exact test
Race				-	0.4008 <sup>1</sup>
White	6 (10.0%)	12 (6.6%)	18 (7.5%)		
Other	54 (90.0%)	169 (93.4%)	223 (92.5%)		
Marital Status				0.3996	.5273
Other Marital Status	29 (48.3%)	96 (53.0%)	125 (51.9%)	0.00000	
Married	31 (51.7%)	85 (47.0%)	116 (48.1%)		
Education				0.1120	.7379
High School and	35 (58.3%)	110 (60.8%)	145 (60.2%)	0.1120	.1317
Above		110 (00.070)	110 (001270)		
Grade 11 or less	25 (41.7%)	71 (39.2%)	96 (39.8%)		
Income				0.5610	.4539
>\$18,001 per year	21 (35.0%)	54 (29.8%0	75 (31.1%)	0.0010	11005
$\leq$ \$18,000 per year	39 (65.0%)	127 (70.2%)	166 (68.9%)		
Depression				0.3423	.5585
Not Depressed	47 (78.3%)	135 (74.6%)	182 (75.5%)	0.3423	.5565
(score <16)	(, , , , , , , , , , , , , , , , , , ,				
Depressed (score	13 (21.7%)	46 (25.4%)	59 (24.5%)		
≥16)					
Social Support				13.1131	.0003
No Social Support	48 (80.0%)	97 (53.6%)	145 (60.2%)		
Social Support	12 (20.0%)	84 (46.4%)	96 (39.8%)		
Housing				4.9645	.0259
Other Housing	7 (11.7%)	46 (25.4%)	53 (22.0%)		·
Own	53 (88.3%)	135 (74.6%)	188 (78.0%)		
House/Apartment	. ,				
Substance Use				2.0010	.1572
No History of	54 (90.0%)	149 (82.3%)	203 (84.2%)	2.0010	.1014
Substance Use		× - )			

**Table 13**Retention and Viral Suppression in  $1^{st}$  Year Postpartum by Covariate, n=241

History of	6 (10.0%)	32 (17.7%)	38 (15.8%)		
Substance Use					
Insurance				6.9066	.0086
Uninsured	1 (1.7%)	25 (13.8%)	26 (10.8%)		
Insured	59 (98.3%)	156 (86.2%)	215 (89.2%)		

Table 14 presents the odds of being virally suppressed. Estimates were only provided for the fifth year postpartum as estimates in the first and tenth year were unstable and resulted in wide confidence intervals. In the fifth year postpartum, those who were retained were three times as likely to be virally suppressed in comparison to those who were not retained and this finding was statistically significant (p-value=.0051).

#### Table 14

Odds of Being Virally Suppressed in the 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> Years Postpartum by retention status,

n=241

Postpartum Year	N of Participants	Effect	Odds Ratio (Point Estimate)	Wald 95% Confidence Limits	<i>p</i> -value
1 <sup>st</sup> Year	241	Retained (1) vs. Not retained (0)	a	a	a
5 <sup>th</sup> Year	157	Retained (1) vs. Not retained (0)	3.119	1.408, 6.912	.0051
10 <sup>th</sup> Year	90	Retained (1) vs. Not retained (0)	a	a	a

 $a^{a}$  = result of unreliable estimates due to small data.

Table 15 examines odds of being virally suppressed by one-pill antiretroviral therapy era. The odds of being virally suppressed were higher for those whose last delivery year was post-2006 in comparison to those who delivered before 2006. This was statistically significant for the first (OR=3.807, p-value <0.0001) and fifth year (OR=2.575. p-value=0.0028) postpartum but

not tenth (OR=1.020, p-value=0.9668).

## Table 15

Odds of Being Virally Suppressed in the 1<sup>st</sup>, 5<sup>th</sup>, and 10<sup>th</sup> Years Postpartum by Antiretroviral

Effect N of Postpartum Odds Ratio Wald 95%

*Therapy Era*, *n*=278

Year	Participants		(Point Estimate)	Confidence Limits	
1 <sup>st</sup> Year	278	Post One-Pill ART (2006- 2017) (1) vs Pre One-Pill ART (2005 and earlier) (0)	3.807	2.218, 6.534	<0.0001
5 <sup>th</sup> Year	233	Post One-Pill ART (2006- 2017) (1) vs Pre One-Pill ART (2005 and earlier) (0)	2.575	1.384, 4.793	0.0028
10 <sup>th</sup> Year	158	Post One-Pill ART (2006- 2017) (1) vs Pre One-Pill ART (2005 and earlier) (0)	1.020	0.408, 2.549	0.9668

# Longitudinal Logistic Regression of Covariates and Retention

Table 16 presents the results of the longitudinal logistic regression, which seeks to determine what covariates/factors were associated with participants being retained over time. WLWH who were not married (OR= 0.6815, p-value = <.0001), had income ≤\$18,000 (OR=0.4706, p-value =

*p*-value

0.0004), no reported source of income (OR=.3383, p-value = 0.0062), no social support (OR=0.6128, p-value = <.0001), did not own a house/apartment (OR=.5113, p-value = <.0001), no insurance coverage (OR=.4926, p-value = <.0001), and no expanded Medicaid (OR=.2509, pvalue = 0.1024) were less likely to be retained in care over time. WLWH who were White (OR=1.1759, p-value=0.5284) or had no history of substance use (OR=1.1322, *p*-value = 0.3379) were more likely to be retained in care over time. Unexpected findings include as age increased, the likelihood of retention decreased (OR=0.983, 0.5572), those who reported to be abstaining from alcohol were less likely to be retained in care (OR=0.4991, p-value=0.0002), those with less than a high school education were more likely to be retained in care (OR=1.7028. pvalue=.0105), and as depression increased the likelihood of being retained increased (OR=1.0380, p-value=<.0001). Although multiple significant odds ratios were found, the increased likelihood of being retained was minimal as evidenced by odds ratios that were scarcely more than 1.

#### Table 16

Covariate	Comparison (0)=reference group, (1) comparison	Estimate	Odds Ratio	95% Confidence Limit Lower	95% Confidence Limit Higher	<i>p-</i> value
Site	Non-Southern (0), Southern (1)	-0.2543	0.7755	-0.5947	1.10333	0.5572
Age at Visit	Increasing Age	-0.0169	0.983	-0.0328	-0.0010	0.0368

Results of Longitudinal Logistic Regression and Covariates related to retention over time.

Race	White (0) vs Other (1)	0.1620	1.1759	-0.3416	0.6657	0.5284
Marital Status	Other Status (0), Married (1)	-0.3835	0.6815	0.1983	0.5687	<.0001
Education	Less than high school (0), more than high school (1)	0.5323	1.7028	0.1244	0.9401	0.0105
Income	Less than 18,000 (0), More than 18,000 (1)	-0.7537	0.4706	-1.1684	-0.339	0.0004
Income Type	Any Income Source (1) (which includes wages, welfare, social/disability, other income, multiple income sources) vs. No Income Sources (0)	-1.0838	.3383	-1.8593	-0.3083	0.0062
Depression	Continuous CES-D score	0.0373	1.0380	0.0195	0.0551	<.0001
Substance use	No Substance use (0), Substance use (1)	0.1242	1.1322	-0.1298	0.3782	0.3379
Alcohol Use	Abstaining (0), Drinking Alcohol (1)	-0.6950	0.4991	-1.0644	-0.3256	0.0002
Social Support	No Support (0), Support (1),	-0.4897	0.6128	-0.6785	-0.3008	<.0001
Housing		-0.6708	.5113	-0.9545	-0.3871	<.0001

	Other Housing (0), Own house/apartment (1)					
Health Insurance Coverage	No Insurance Coverage (0), Insurance Coverage (1)	-0.708	.4926	-0.9738	-0.4423	<.0001
Medicaid	No Expanded Medicaid (0), Expanded Medicaid (1)	-1.3827	0.2509	-3.0421	0.2767	0.1024

#### Southern and Non-Southern Sites Retention

The sample was examined by site over time but were only able to examine the first year postpartum as the Southern participants did not have enough follow-up time for later years to be examined (Table 17). No significant difference was found between the Southern (18.2% not retained and 81.8% retained) and the non-Southern sites (39.0% not retained and 61.1% retained) when it came to retention in the first year postpartum (p-value=.2147) (Table 17).

Chi-square analyses were done on three levels of retention, 41% (median), 70%, and 80% based on southern versus non-southern site. As stated earlier, this proportion represents the percentage of years the retention criterion was met during the participant's postpartum interval. The chi-square analyses examined differences based on groupings of southern site designation and retention proportion (four groupings). Table 18 depicts a significant difference between groups based on site and median retention proportion (p-value = 0.0385) for Southern sites.

Proportion of Retention by Year and Southern versus Non-Southern Site, n=278

Postpartum Year	N of Participants	Non- Southern	Southern	Chi square /Fisher's
		N (%)	N (%)	Exact Test p- value
1 <sup>st</sup> Year	278			
Not Retained		104 (39.0%)	2 (18.2%)	$.2147^{1}$
Retained		163 (61.1%)	9 (81.8%)	
5 <sup>th</sup> Year	233		``´´´	
Not Retained		137 (58.8%)	-	
Retained		96 (41.2%)	-	
10 <sup>th</sup> Year	158	× /		
Not Retained		84 (53.2%)	-	
Retained		74 (46.8%)	-	
		` '	-	

*Note*. X<sup>1</sup>=Fisher's Exact Test r/t expected counts less than 5 in cells

# Table 18

Postpartum Period (Time After Last Live Birth) Retention Proportions by Southern Site, n=283

Retention (%)	Non-Southern	Southern	Test Statistic	Chi-Square
	N (%)	N (%)		<i>p</i> -value
Median			4.2840	0.0385
Retention				
≤41%	136 (50.0%)	2 (18.2%)		
>41%	136 (50.0%)	9 (81.8%)		
70% Retention				0.1093 <sup>1</sup>
≤70%	226 (83.1%)	7 (63.6%)		
>70%	46 (16.9%)	4 (36.4%)		
80% Retention				$0.2370^{1}$
≤80%	250 (91.4%)	9 (81.8%)		
> 80%	22 (8.1%)	2 (18.2%)		
Note $X^1$ =Fisher's	Exact Test r/t expe	cted counts less than	5 in cells	

*Note*.  $X^1$ =Fisher's Exact Test r/t expected counts less than 5 in cells

# Hypothesis 2.2: Southern Sites and Retention and Viral Status

A logistic regression was used to answer Hypothesis 2.2 and evaluate the odds ratio of being retained and/or virally suppressed in the first postpartum year in the southern versus non-southern. The odds of having the optimal outcome were higher in the Southern sites (p-value=0.0063). This means that those in the Southern sites were more likely to be retained and virally suppressed in comparison to those in the non-Southern sites. Due to instability in the model creating extreme estimates, the odds ratio or other statistical estimates were not reported for these results.

**Retention/Viral Status Odds Ratios (ORs) with Covariates**. The odds of being retained and virally suppressed (optimal) versus not (suboptimal) were determined for each factor from the Anderson Model based on the first year postpartum (Table 19). Predictors that were significantly associated with retention and viral suppression (*p*-value < .05) were social support (OR=3.464, p-value=0.005) and housing (OR=2.580, p-value=0.0301). The statistical estimates for insurance were not reported related to instability in the model. Statistical estimates for race were not reported as indicated by less than 5 cell counts and Fisher's exact test, the assumptions for logistic regression were not met.

#### Table 19

Odds of Being Retained and Virally Suppressed by Predisposing and Enabling Factors for First Year Postpartum

Predictor	Odds Ratio	Wald Confidence Limits	P-value
Race – White (0) vs. Other (1)	* -	* -	* _

Marital Status – Married (0) vs. Other Relationship Status (1)	1.207	0.673, 2.166	0.5275
Education – High School and above (0) vs. Grade 11 or Less (1)	1.107	0.611, 2.004	0.73380
Income Levels - > 18,0001/yr (0) vs. <\$18,000 (1)	1.266	0.682, 2.351	0.4544
Depression (CESD)- No Depression (0) vs. Depression (1)	1.232	0.612, 24.79	0.5589
Substance use – No Substance use (0) vs. Substance use (1)	1.933	0.766, 4.879	0.1630
Social Support – No Social Support (0) vs. Social Support (1)	3.464	1.726, 6.953	0.0005
Residence –Own House/Apartment (0) vs. Other Housing (1)	2.580	1.096, 6.074	0.0301
Insurance - Insured (1) vs. Not Insured (0)	*	*	* -

-\* = statistical estimate not reported due to instability in the model and/or not meeting

assumptions for test

# Aim 3: Survival Probabilities and Cox Regression Models

This section presents the survival probabilities and Cox regression models of the sample to answer aim 3 to examine the effects of the predisposing and enabling factors on health behavior (retention in care) and health outcomes (mortality and viral suppression) based on the Andersen Behavioral Model of Health Services Use. This is to test the hypothesis (H3) that: Low retention in care (not having at least two health care visits in a 12-month period) will be influenced by contextual (southern versus non-southern), predisposing factors (age, race, marital status, education, income/employment, depression, and substance abuse) and enabling factors (social support, housing, and health insurance coverage) and associated with higher rates of mortality. The ABM assumes that predisposing and enabling factors are predictors for various health issues.

First, survival at different levels of postpartum retention and years until care interruption is shown in Table 20. Next, the results are presented of how survival differs because of predisposing or enabling factors. A univariate Cox regression analysis was performed to determine the hazard ratio for mortality. A multivariate Cox regression analysis was also performed to build a model predicting survival (time to death).

#### Table 20

Variable	Chi-Square Test Statistic	Log-rank p- value
41% Retention	0.7104	.3993
70% Retention	0.5924	.4415
80% Retention	2.5701	.1089
Years till care interruption	1.9484	.8562

Survival by Retention Proportion

There were no significant differences in survival in all levels of retention including median retention (~41%) (p-value=.3993), 70% (p-value=.4415), and 80% (p-value=.1089).

When examining retention only in the first year of the postpartum survival, a significant difference was not found (p-value = .3592). The sample was examined by years until care interruption (as in how many years participants were retained after the last date of delivery until the endpoint of 2017 or the year of death). The years until care interruption ranged from zero to five years. There was no significant difference in survival in regard to years until care interruption (p-value-0.8562)

 Table 21. Non-parametric Estimation of Survival

Variable	Chi-Square	p-value	
Turane	7.0517	0.0070	
Income Substance Use	7.0517 18.6738	0.0079 <.0001	

## Table 22.

Parametric Estimation of Survival from Univariate Cox Models

Variable	Chi-Square Test Statistic	Log-rank p- value	Hazard Ratio
Age	5.1432	0.0233	1.071
Income	6.2654	0.0123	3.296
Substance Use	1.27126	< 0.0001	3.565

Model of Survival

Variable (reference category=0)	Test Statistic	p-value	Hazard Ratio
Age	6.6822	0.0097	1.085
Income (Income Greater than \$18,000)	4.8484	0.0277	0.344
Substance Use (No History of Substance Use)	12.7147	0.0004	0.317
Median Retention Proportion (Postpartum Retention Proportion less 41%)	0.0000	0.9944	0.998

In the non-parametric estimation, survival was significantly different for two factors: income (log-rank *p*-value = .0079), and substance use (*p*-value = < .0001) as seen in Table 21. Age was also significant factor whereas age increased the likelihood of mortality increased (HR=1.071, p-value=0.0233). All other factors were nonsignificant (p-value >.05). Using the class statement in the univariate Cox analysis, those who had an income less than or equal to \$18,000 (*p*-value = .0123; HR = 3.296), and history of substance use (*p*-value = < .0001; HR = 3.565) were found to be more likely to experience mortality as seen in Table 22. In summary, these groups were more likely to expire over the study period. Significant variables/predictors of age, income and substance use were then built into a multivariate Cox regression model. The median retention proportion were also included in the model. After building this model age (*p*-
value = .0097; HR = 1.085), income (*p*-value = .0277; HR = 0.344), substance use (*p*-value = .0004; HR = 0.317) were significant for predicting survival. Median retention proportion was not significant where those with less than 41% of their postpartum retention in care had marginal odds for predicting survival (*p*-value=0.9944, HR=0.998). As evidenced by the hazard rates less than 1, those had higher income and had no history of substance use were less likely to experience mortality. The Schoenfeld test of residuals was used to check the hazard assumption for the continuous variable of age, and it appears, according to the specified smooths, that the coefficient for this covariate did not change over time as evidenced by the specified smooths clustering around zero. In other words, the effect of age on the hazard rate is constant over time and the proportional hazard assumption is not violated. Figures 6 and 7 show the Kaplan Meier curves for the categorical predictors of income and substance use. Each tick represents a censor and people were censored by death until study end period of 2017.







Figure 7. Plots of Kaplan-Meier product limit estimates of survival of participants by income

#### **Chapter 5: Discussion**

This study was a secondary analysis of data from the Women's Interagency HIV Study (WIHS), a national cohort study examining the characteristics and outcomes of WLWH in the US (Adimora et al., 2018). Guided by the Andersen Behavioral Model (Andersen, 1995), this study evaluated the predisposing and enabling factors posited to influence retention in care, viral suppression, and mortality in 283 WLWH who gave birth following enrollment between 1994 and 2017. This study had three aims: (1) to determine the time from the date of last delivery to death for postpartum WLWH; (2) to determine the proportion of postpartum women defined as any woman reporting a live post-enrollment birth, retained in care (defined as at least two healthcare visits in in 12 months) in the current study for each calendar year between 1994 and 2017, and whether retention was associated with viral suppression; and (3) to determine the effects of the predisposing and enabling factors on health behavior (i.e., retention in care) and health outcomes (i.e., mortality and viral suppression) based on the ABM.

This chapter presents a discussion of these findings and is divided into the following sections: a) sample characteristics; b) survival estimates, including mortality; c) retention over time; d) retention and viral suppression; e) significant factors from the Andersen Behavioral Model; f) study's strengths and limitations; g) future directions, and h) implications for research and clinical practice.

# **Sample Characteristics**

# General Demographic Characteristics

Participants in this study tended to be older than average for mothers as they were closer to advanced maternal age at the time of their last live birth, with an average age of 33 years.

The sample in this study did not reflect the major US trends in HIV as it primarily consisted of women from non-Southern states. The incidence of HIV diagnoses is 9.4 per 100,000 in the Northeast, 9.2 per 100,000 in the West, and 7.2 per 100,000 in the Midwest, rates that are all lower than in the South, where the incidence is 15.2 per 100,000(U.S. Department of Health & Human Services, 2021b). Florida, Texas, and Georgia are among the five states with the highest incidence of HIV in women and girls. Only 11 participants from Southern states met the inclusion criteria in this sample. Table 24 presents a comparison of this all-female sample with estimates gathered by the CDC for both men and women with HIV in the United States in its most recent 2015 cycle (CDC, 2020a). Notably, retention and viral suppression were low in the current sample for the first year postpartum compared to national estimates for the past 12 months. Depression was nearly double the national estimate for all adults, with 12% nationally versus 23.7% for this sample, and a high proportion of the sample reported unstable housing or unmet housing needs. Concerning race and ethnicity, the majority of the sample was non-white, with a significantly lower proportion of white participants (8.5%) than the national estimate of 30% for all adults. Reasons for this lack of similarity include an all-female sample and the changing demographics of HIV in a sample that goes back to 1997.

Characteristic	Sample Proportion (%)	National/CDC Surveillance
		Proportion
		(CDC,
		2020a)(%)
Health insurance	89.1%	98%
Less than high school education	41.0%	46%
Major depression	23.7%	12%
Substance use	14.8% with any history of substance use	29% for any non-injection drugs
		3% for any injection drugs
Retention in care	61.9% for first year postpartum	80% for past 12 months
Viral suppression	29.5% for first year postpartum	63% virally suppressed at all tests in the past 12 months
Unstable housing	21.6%	12%
Race Ethnicity	8.5% White	30% White
	91.5% Other	70% Other

Table 24. Sample characteristics versus national surveillance

#### Aim 1: Time from Date of Last Delivery to Death

For the current study, Aim 1 was to determine the time from the date of last delivery to death for this sample of WLWH who enrolled and delivered between 2004 and 2017. Survival analysis was performed to determine the influence of predisposing and enabling factors on the likelihood of experiencing mortality for this group of participants from the WIHS study.

## Mortality and Predisposing Factors

The overall mortality rate was low in the sample, with less than 15% of the sample experiencing mortality. This made it impossible to calculate the median mortality time. The mean survival time (follow-up time for those who were alive) was 15.1 years, which was relatively short when compared to the study period of 23 years, especially after having a live birth. The predictive factors found to be associated with mortality included age, race, income, and substance use. Comparisons between Southern and non-Southern sites were impossible since no deaths were reported in Southern sites. An association between age and mortality was expected since older age is often associated with death. In this sample, the risk of death was elevated by a factor of three for those with an income of less than \$18,000 or who had a history of substance use. Previous research on PLWH, including women, has shown that those with a lower income or socioeconomic status can have different priorities when compared to those with a higher income. All the factors above can impact the access to and maintenance of medical care, adequate nutrition, and shelter (McMahon et al., 2011; Riley et al., 2007). There are common difficulties for WLWH, who may also have unmet childcare needs and associated expenses (Riley et al., 2007). ). Regarding history of drug use, previous research indicates that active drug use can hasten the progression of HIV by increasing the viral load and can worsen the AIDSrelated mortality (Dash et al., 2015). Those with a history of substance abuse are less likely to

receive antiretroviral therapy or to undergo viral load testing, which is important in monitoring the progression of HIV disease (Raboud et al., 2005). Despite the improvements made in lowering mortality among those living with HIV and treating substance use disorders, mortality among those with a history of substance use continues to remain higher than for those without (Ramaswamy, 2020). For these reasons, linking people with HIV and a history of substance use to necessary services for HIV, substance abuse, mental health, and other wraparound services is essential to improve HIV mortality outcomes (Iroh et al., 2015). For patients who died, the average time to death was 10.1 years. Reflected in these statistics is the influence of predisposing sociodemographic factors on the health and wellbeing of WLWH.

## Aim 2: Postpartum Retention and Viral Suppression: Likelihood of Optimal Outcomes

For Aim 2, multiple analyses were conducted to examine the proportions of women who were retained and virally suppressed. Comparisons were made between Southern and non-Southern sites and predisposing and enabling factors. The results suggest that certain factors are associated with optimal outcomes in some contexts but not others. The study's definition of retention and its sample size made comparisons with the previous research difficult, and few studies besides this examined women more than two years postpartum.

#### **Retention in Healthcare**

This study is one of the first to describe retention in care among postpartum WLWH for a period of more than two years after delivery. The postpartum WLWH in this sample were found to have low rates of retention and viral suppression for up to 20 years after delivery. Of the estimated 255,900 WLWH in the U.S. in 2014, 50% were retained in care and 48% achieved

viral suppression (CDC, 2018). In contrast, in this study, at one year postpartum, less than 25% of the sample was retained and virally suppressed after the delivery of their last child.

Retention in care among these 283 WLWH was low, with 61.9% and 46.8% retained at 1 and 10 years postpartum, respectively. While previous studies have reported low postpartum retention in care among WLWH (Adams et al., 2015; Buchberg et al., 2015; Rana et al., 2010; Siddiqui et al., 2014; Swain et al., 2016), the long-term retention estimates for this group of postpartum WLWH were even lower than in previous reports, i.e., 34% at two years for an Atlanta cohort and 78% after 10 years of follow-up for a Nashville cohort (Meade et al., 2019; Oliver et al., 2019). In this sample, the majority (58.3%) of patients who were retained and virally suppressed at one year postpartum had an education level of high school completion or above. Similar to previous research, most of the patients without a history of substance abuse were retained and virally suppressed at one year postpartum (Hodgson et al., 2014).

#### Characteristics of Participants with Low Retention

Age, education level, and housing situation were found to be significantly associated with the number of postpartum years of retention in care after the last live birth. Women with retention below the median of 41% were on average 32–33 years old at the time of their last delivery, making them around a year younger than those with retention above the median (see Table 1). This is consistent with previous studies to show that younger women—typically below 30 years of age—are less likely to remain in care than those who are older (Chen et al., 2019; Knettel et al., 2018; Obasanjo & Kumwenda, 2009; Orne-Gliemann et al., 2017). The present findings emphasize the need to establish HIV care engagement at an early age and then continue to emphasize the importance of attending HIV care regularly, for long-term retention. In the current sample, women with a level of education below high school completion represented a greater share of patients with retention below the median, 44.2%, compared to 38% of patients with retention above the median. This finding is consistent with those of Ayuo et al. (2013) and Bardeguez et al. (2008), who found that a low education level was associated with failure to attend follow-ups and low ART adherence (Ayuo et al., 2013; Bardeguez et al., 2008). Ayuo et al., 2013 found that for each additional year of education, the likelihood of perfect adherence increased by 10.6% (Ayuo et al., 2013). A low education level may hinder patients' understanding of HIV care (Bardeguez et al., 2008). When studying the relationship between education and adherence, Bardeguez et al. (2008) found that low health literacy was a barrier to understanding the HIV disease process and different treatment options. Low education and health literacy have also been found to be associated with patients' decreased ability to follow healthcare instructions (Bardeguez et al., 2008; Kalichman & Rompa, 2000).

Housing status was significantly associated with retention. Women who were in unstable housing or did not have their own house or apartment represented 27% of those with retention below the median. The overall proportion of those with other housing or who were not living in their own house/apartment was 21.6% of the sample. Few studies have explicitly examined the link between housing and postpartum retention in care. In general, research on HIV retention in care and patient outcomes has shown that those with unstable housing are less likely to be virally suppressed or retained in care (Aquino et al., 2021; Riley et al., 2019). These studies suggested that patients in unstable housing may need additional support services as standard retention-in-care strategies may not achieve viral suppression. Further research is warranted to examine the relatively fixed predisposing and enabling factors of healthcare utilization such as age, education, and housing. The existing evidence, including the findings of the present study, suggests that the

sociodemographic status during pregnancy and the postpartum period may have long-term implications for HIV care outcomes in postpartum WLWH.

## Understanding Long-Term Retention and Predisposing/Enabling Factors

The HIV care continuum is crucial to understanding long-term retention. As previously stated, the HIV care continuum outlines the steps or stages through which patients with HIV progress, from their diagnosis to achieving and maintaining viral suppression. Individuals may enter or leave the care continuum at different stages. This was reflected in the WIHS study, where participants entered, left, and reentered the study over their lifespan. When examining long-term retention in care, or specifically the influence of each predictor on the repeated measure of retention in this sample, it was found that most of the predictors such as age, marital status, education, income, income type, depression, alcohol use, social support, housing, and health insurance coverage were significantly associated with retention. According to the Andersen Behavioral Model, these predisposing and enabling factors were expected to influence health behaviors such as retention. However, the magnitudes of the results (odds ratios of less than 2) are not practically significant. In other words, though statistically significant, limited inferences can be made about the influence these predictors have on long-term retention, as most of them suggest relatively similar odds for both groups (e.g., married versus unmarried). Despite the lack of a substantial impact on retention outcomes, these results support the ABM as they show the influence of predisposing and enabling factors on health behaviors such as retention in care.

#### **Retention and Viral Suppression**

The main two outcomes of interest in this study were retention in care and viral suppression. Though the current study was unable to determine the retention directly, it examined viral suppression in this rich excerpt of data from the WIHS spanning over 10 years. The current study could thus describe the long-term viral suppression and also examine the relationship between viral suppression and retention in this vulnerable population.

## **Retention as a Predictor of Viral Suppression**

Engagement with HIV care is essential for all WLWH as it greatly improves their chance of achieving viral suppression and positive outcomes. Specifically, retention in HIV care, which is traditionally defined as two healthcare visits at least three months apart, is an important part of the care continuum as poor retention rates are associated with lower rates of viral suppression (Crawford, 2014; Yehia et al., 2014). Approximately 50% of patients with HIV in the US were retained in care in 2021 (U.S. Department of Health & Human Services, 2021a). Of those, 1.3 million (57%) were virally suppressed. The percentage of HIV-positive individuals who are both virally suppressed and retained in care in the United States is below the 95-95-95 UNAIDS worldwide target for 2030 (Unaids, 2015). For the first year postpartum, 61.9% of the women in the sample were retained and 29.5% were virally suppressed. Although the retention rate in this sample was better than the overall US estimate, it was still below the UNAIDS goal. Furthermore, women in this sample failed to achieve retention and viral suppression at one year postpartum at rates similar to those of other US WLWH populations (Meade et al., 2019; Swain et al., 2016). In this sample, only 24.1% achieved the optimal outcome where they were retained in care and virally suppressed at one year postpartum. This is consistent with previous investigations, which found that patients with poor viral suppression were less likely to be

retained in care (Oliver et al., 2019) underlining the unique challenges faced by this vulnerable population concerning HIV care and highlighting the need for further related studies.

The most common predictor, when examining postpartum HIV outcomes, is the retention in care at one year postpartum. In the present study, retention was examined at 1, 5, and 10 years postpartum, but estimates could only be obtained for the fifth year postpartum due to instability in the model. In the fifth year postpartum, those who were retained were more than three times as likely to be virally suppressed than those who were not retained. Though the increased likelihood of viral suppression with retention is not a new finding, this statistically significant positive finding reflects the importance of being retained in care. Previous research has indicated the most important predictor of retention and viral suppression is early postpartum HIV care engagement, which is often defined as engaging with HIV care in the first 90 days after delivery. Though this study was unable to determine the engagement with HIV care during the first 90 days after delivery, the influence of retention on outcomes such as suppression and mortality was assessed by examining the proportion of years for which the participants met the retention criterion, from their last delivery until either their death or the end of the examined study period in 2017.

As shown by both the current and previous results, postpartum retention in care and viral suppression are essential for achieving favorable long-term HIV care outcomes (Meade et al., 2019; Meade et al., 2018). Yet, there is evidence of viral rebound and treatment discontinuation during the postpartum period (Sha et al., 2011). Even in WLWH who achieve viral suppression before delivery, there is a major risk of a lack of viral suppression and disengagement from HIV care during the postpartum period. Factors considered to be associated with this phenomenon include the high rates of nonadherence, medication interruptions, and medications changes or

discontinuations that occur in the early postpartum period (Grant et al., 2009; Riddler et al., 2008; Sha et al., 2011). Often, women neglect their health to focus on their infant(s), as reported when discussing their reasons for not attending visits and their decreased adherence rates postpartum compared to during pregnancy (Bardeguez et al., 2008; Buchberg et al., 2015). Continuing to understand how retention can influence viral suppression is important to improve the outcomes and achieve appropriate retention and viral suppression rates in this population.

#### Viral Suppression and Retention Over Time

Previous studies have examined retention in care and viral suppression separately (Adams et al., 2015; Meade et al., 2019). But the current study included retention in care and viral suppression as a combined outcome, where being both retained and virally suppressed was optimal. Being retained but unsuppressed, not retained but virally suppressed, or not retained or suppressed were suboptimal outcomes. At one year postpartum, 24.5% of the sample was retained and virally suppressed, while 75.1% was considered to have a suboptimal outcome. Other studies that evaluated retention and viral suppression in similar populations in Philadelphia and Atlanta found that about one-third of women were virally suppressed in the first year after delivery (Adams et al., 2015; Meade et al., 2019). These studies evaluated the HIV outcomes at both one and two years postpartum. Their findings fell well below the goal of UNAIDS that less than 5% of patients with HIV should be left unsuppressed. In this study, at one year postpartum, 32.8% of the sample were not retained or suppressed, which increased to 44.6% of those who were alive and still participating in the study at the fifth year postpartum. Koss and colleagues study, that had a comparable follow-up period (more than 2 years), found that 90% of their sample of Ugandan women were retained in care and 80% were virally suppressed up to 5 years after initiating ART during pregnancy (Koss et al., 2017). However, their definition of retention

in care was "having attended an HIV care visit in the last 90 days," which does not meet the criteria set by the US Health and Human Services of "at least two visits at least three months apart." Though postpartum care engagement has been established as an important predictor of retention at one and two years postpartum (Adams et al., 2015; Meade et al., 2019), the analysis of this sample of postpartum WLWH suggests that complex factors influence retention and viral suppression over time and that often care received in the first year is not maintained over time.

Changes in the proportion of retained and suppressed participants were expected over time, particularly considering the longitudinal nature of the present study. However, after 10 years of survival and follow-up, the proportions of those retained and virally suppressed remained constant at between 20 and 30%. The proportion of those retained alone among participants who were still alive and had follow-up data decreased from 61.9% at one year postpartum to 46.8% at 10 years postpartum, though these results may have been affected by the implicit capture of retention information through the healthcare utilization questionnaire. The proportion of patients who were virally suppressed alone at 10 years postpartum was 31.7%, representing only a marginal increase from the proportion at one year postpartum (29.5%). According to the ABM, these changes were influenced by both predisposing and enabling factors. As mentioned above, how predisposing and enabling factors influence the health behavior of retention, which in turn, influences viral suppression and mortality outcomes, was key to the current framework. The low retention and viral suppression rates reported in this study, along with the trends observed over time, suggested the need to improve retention alongside viral suppression. This notion is further supported by the finding that the proportion of retained but unsuppressed patients steadily decreased from 39.8% at one year postpartum to 30% at 10 years postpartum. Rather than seeing an increase in the proportion of individuals being

retained and suppressed, the proportion of those not retained or suppressed remained the largest of the four groups of participants (at 42.2%) who were alive and had at least 10 years of followup data. Despite the possibility that some postpartum WLWH may seek care at multiple clinics, the transition from obstetrics and gynecological care back to HIV or primary care, and disruptions in care due to housing changes or incarceration, may make achieving and maintaining viral suppression challenging for postpartum WLWH (Yehia et al., 2015). Though virally suppressed WLWH may not need to receive HIV care as often as those who are unsuppressed (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2019), the lack of viral suppression suggests the need to explore some of the predisposing and enabling factors that influence other HIV-related healthcare behaviors such as taking medication and refilling prescriptions.

The current study is among a small number to have reported on viral suppression beyond two years postpartum in a high-resource setting. There were low levels of viral suppression (<30%) overall in the sample, and even lower levels of the optimal outcome of being both retained and virally suppressed (<25%) over the study period. Most of the limited existing data on retention and viral suppression in this vulnerable population focus only on one to two years postpartum, with variation by practice setting and the frequency of viral load testing. Moreover, previous studies used different thresholds for retention, making comparisons across studies challenging. A study of 150 women in Uganda, for example, found that 80.7% of participants demonstrated viral suppression to <400 copies/ml at a median time point of 4.2 years (Koss et al., 2017). In a prospective cohort study of over 1416 women in North Carolina, meanwhile, 42% of the women tested had HIV RNA <400 copies/ml at 24 months postpartum, but only 25% of the women maintained viral suppression for both their first and second years postpartum (Chen

et al., 2019). Then, in a cohort of women who delivered between 2005 and 2011 that focused primarily on postpartum care engagement within 90 days after delivery, and in which retention was defined as taking multiple CD4/viral load tests in each six-month interval at greater than 60 days apart, while viral suppression was defined as <200 copies, 25% were retained in care and 34% were virally suppressed at two years postpartum (Adams et al., 2015). Taken together, these results and the previous research indicate a need to improve retention in care and viral suppression in this population. However, more standardized definitions and outcomes, such as examining retention and viral suppression separately versus together as one outcome, are needed. For example, the standard definition of viral suppression changed over time from greater than 400 copies to greater than 200 copies. The current study also covered the transition to the onepill or single-tablet regimen era in 2006. Similar to the wider literature, there was improved virologic suppression after the advent of the single-tablet regimen (Franco et al., 2002; Parienti et al., 2009). Hanna and colleagues found improved virologic suppression among a cohort of women with adoption of a single tablet regimen (Hanna et al., 2014). However, they noted that 15% of women prescribed ART were still not optimally adherent and that interventions were needed to maximize the therapeutic benefit. In the current study, the likelihood of viral suppression was the largest in the first year postpartum when the last delivery year was after 2006; these women were 3.8 times more likely to be virally suppressed than those who delivered before 2006. However, the rates of viral suppression were below the target and similar to those found by Hanna and colleagues, which suggests that other interventions are needed to maximize the benefit of single-tablet therapy.

#### **Significant Factors in the Andersen Behavioral Model**

In the present study, multiple analyses were conducted to evaluate how predisposing and enabling factors influence retention and other outcomes, including viral suppression and mortality. Considering the analyses as a whole, several factors were found to be consistently significant in terms of influencing the outcomes of interest. Among the predisposing factors, age, race, income, and substance use were found to be the most consistently significant factors. Despite the noteworthy results of better retention and viral suppression in Southern postpartum WLWH, the small sample of 11 participants limits the inferences that can be made regarding the influence of the Southern context. Meanwhile, the only enabling factor found to have significantly influenced retention was housing. The existing postpartum retention in care research identified most of these factors; however, this study produced novel insights into which factors increase or decrease the likelihood of retention and viral suppression, particularly from a longitudinal perspective.

#### **Predisposing Factors in the Framework**

#### Income.

Economic insecurity and poverty are known obstacles to accessing HIV care and treatment services (Centers for Disease Control and Prevention, 2019). Resource-limited settings, such as those in multiple African countries, tend to have the largest concentration of HIV burden as the costs of seeking care can prevent patients from adhering to ART and engaging with care (Swann, 2018). ). Lack of transportation, the need to take time off from work or other productive economic activities, and insufficient insurance coverage to meet healthcare costs create significant barriers to treatment and care. Poverty may force patients with HIV to choose between paying for medications and HIV care or covering their basic needs such as housing and groceries. In the current study, a higher income protected against mortality and was associated with postpartum retention in care. These findings suggest that having the resources and flexibility to engage with care and comply with HIV treatment over time can improve the outcomes of patients with HIV. Postpartum WLWH on a lower income may face unique psychosocial challenges around depression and social support, which may in turn, influence their ability to attend HIV care appointments and take ART as prescribed(Akinde et al., 2019).

## General Substance Abuse, Including Alcohol.

Substance abuse increases a person's risk of acquiring HIV because it may make them more likely to engage in risky behavior, such as unprotected sex or using needles that have not been properly cleaned to inject drugs. Injection drug use is responsible for only a small proportion of HIV diagnoses (1/10), but the role of general substance use in the prevention and transmission of HIV, as well as engagement in care, is important (Centers for Disease Control and Prevention, 2021a). Despite previous literature reporting that those with substance use disorders, including those with a previous history of substance use, are more likely to miss care appointments and use emergency care services, no significant difference was found in the retention results between those with and without a history of substance use and mortality. Those with a history of substance use were 3.5 times more likely than those without to experience mortality. Previous clinical research indicates that substance use and addiction may worsen AIDS-related mortality even among individuals who follow antiretroviral regimens (Dash et al., 2015). Furthermore, individuals with substance use disorders are less likely to take HIV medication regularly, which can worsen the course of the HIV disease, and in turn, put them at risk of mortality (Campbell et al., 2013).

Previous studies reported an association between a history of drug abuse, poor retention in care, and mortality (Oliver et al., 2019). In this study, the proportion of individuals with a history of substance use was 14.8%, more than one-tenth of the sample. This proportion was comparable to that of a previous study that examined postpartum retention in care in WLWH(Adams et al., 2015). Those in the sample without a history of substance use were 1.13 times more likely to be retained than those with such a history. Yet, the odds of retaining those with a history of substance use were marginally better than those found in a sample of adults living with HIV in an urban clinic; the authors of the previous research suggested that treatment of substance use and mental health can improve the retention in care for this population (Marx et al., 2011).

The current study also reported on alcohol use, which has important connections with substance use and retention. The majority of participants were considered to be abstainers, but 31% reported they drank alcohol. No meaningful relationship was found between retention and alcohol use. The existing research found mixed results regarding the impact of alcohol use on health service utilization including retention in care. In Azar and colleagues' (Azar et al., 2010) systematic review of the impact of alcohol use disorders on healthcare utilization, of the seven studies examining the impact on outpatient visits, three found an association between alcohol use disorders and decreased utilization of outpatient sources (Cunningham et al., 2006; Gordon et al., 2006; Kim et al., 2006), two studies reported increased use (Cunningham et al., 2006; Kraemer et al., 2006), and two did not find a significant association (Cunningham et al., 2007; Masson et al., 2004). One reason for this discrepancy may be that those with alcohol use disorders could visit

clinics for drug treatment or psychiatric care rather than HIV care. Another reason may be that those with a heavy alcohol intake might use acute care services, such as emergency rooms and hospitalization, more than routine outpatient services.

# Age.

As previously stated, the influence of age on retention and viral suppression was mixed. The results of the present study suggest a need to holistically examine how age and unmet needs, such as housing, influence HIV care outcomes.

## **Enabling Factors in the Framework**

# Housing.

Postpartum WLWH who lived in their own house or apartment were over three times more likely to be retained in care and virally suppressed than those who did not live independently. The association between stable housing and HIV outcomes is well-documented. In a study of out-of-care women of color living with HIV (Rajabiun et al., 2020), housing was the second most commonly expressed need after transportation; these and other unmet needs were commonly observed among patients aged over 40 years.

Despite the challenges such needs present, there is evidence that the impact of unstable housing can be mitigated. Hawk et al. found that participants successfully moved through the HIV care continuum—being engaged and retained in care and also virally suppressed regardless of their housing status (Hawk et al., 2019). This finding, along with those of previous studies, suggests that evidenced-based support and services might mitigate the impact of unstable housing on retention in care and viral suppression.

#### Social support.

Retention has been reported to be compromised by lack of social support (Knettel et al., 2018). The type of social support is particularly important, as women living with HIV report a lack of social support outside of immediate family members (Buchberg et al., 2015). In Hoffmann and colleagues' study of Malawian women, those who had support while taking antiretroviral therapy were more than three times as likely to be retained in care (Hoffman et al., 2017). In the present study, there were conflicting results in the sample concerning social support. In the longitudinal logistic regression analysis, those without social support were less likely to be retained in care, as evidenced by an odds ratio of less than 1. This finding was statistically significant and as expected. However, when examining retention and viral suppression together, those without social support were over three times more likely to be retained and virally suppressed than those with social support. In their systematic review of the ABM, Babitsch and colleagues noted the wide application of the model and the use of secondary data sets, which may have contributed to large variations in the way variables were categorized, especially in terms of predisposing and enabling factors (Babitsch et al., 2012). Social support was not a commonly measured enabling factor when compared to the health insurance status, usual source of care or family doctor, and financial situation. Babitsch and colleagues suggested that the context of these studies and the characteristics of the study populations appeared to strongly influence the existence, strength, and direction of these associations. Several limitations of the current study most likely contributed to conflicting findings, including the changes to the availability of the social support questionnaire and since nearly two-thirds of the sample were considered to be without social support. As mentioned earlier in Chapter 3, the questionnaires for WIHS changed over time. The social support questionnaire was not available at all visits and so

participants did not have an equal opportunity to answer those questions at the same point after delivering their last child. Unlike with retention, where evidence of viral suppression could be used as a surrogate measure, there was no surrogate measure for social support. Previous evidence, and to a small extent the current study, support the importance of addressing social support. On a broader level, primary studies must develop a knowledge base for healthcare utilization measures like retention in women living with HIV, to further clarify the complexity of the ABM processes (Babitsch et al., 2012).

## Aim 3: Retention as a Predictor of Mortality

No significant difference in mortality was observed for different levels of retention in care, including at 41% (i.e., the median retention for the sample), 70%, and 80%. In other words, the level of retention appeared to have no statistically significant association with mortality, though the results should be interpreted with caution due to small sample sizes at the 70% (n = 50) and 80% (n = 24) levels. As stated earlier, in Chapter 2, measurements of retention and mortality have greatly varied between studies based on the contexts and definitions used. Most maternal mortality studies are conducted in low-resource settings where the event of death is much more frequent. Yet, with the changing landscape of maternal health and enduring maternal mortality and morbidity crisis in high-resource settings like the United States, greater awareness and improved care standards are needed, which will support better comparisons between studies and thus limit the poor outcomes for women (ACOG, 2022). The current study contributed to developing better comparisons by using the ABM as a theoretical framework.

## **Revised Andersen Behavioral Model**

Figure 8 illustrates the theoretical model used in this study following data analysis. In summary, the findings of the present study support the research hypothesis that predisposing and enabling factors are predictive or associated with retention in care, viral suppression, and mortality. The hypothesis that patients who are retained in care are more likely to be virally suppressed was supported. However, the data were not sufficient (containing a small proportion of participants from Southern sites) to evaluate the differences between Southern and non-Southern women.



Figure 8. Final Andersen Behavioral Model for this Study

# **Study's Strengths**

The present study had several strengths. First, it had a large sample size of 283 postpartum WLWH. Second, we accessed a wide collection of clinical and social data that were collected at six-month intervals. The longitudinal nature of this study allowed for rich inferences

to be made about retention and viral suppression over time and for longer periods than most reported studies to date. The sampled data contained both measurements over a long period and for an established scientific cohort. The interval cohort design of the parent study was an advantage as the data for most of the sample were more uniform-and in some instances, more complete—than those of a clinical cohort. The inclusion of participants outside of clinical settings also allowed women's experiences to be captured who may not have regularly engaged with care and thus would have been missed from a clinic-based cohort. Though the duration of follow-up created an opportunity to examine long-term retention and viral suppression, it limited the comparisons that could be made with previous research on a short follow-up period. Nonetheless, spatially, despite the Southern sample being small, this study was able to gather information from diverse geographic locations across the continental United States, giving it a generally diverse sample (Adimora et al., 2018). The WIHS is the oldest and largest ongoing cohort study following women living with HIV and at-risk women (Adimora et al., 2018; Bacon et al., 2005), and it remains the leading source of information about the experiences and health of women living with HIV in the United States.

## **Study's Limitations**

The present study had several limitations. First, the small number of women from Southern states (n = 11) limited the inferences that could be made regarding differences between Southern and non-Southern sites. A possible explanation for this low number is that the median age of patients in the recruitment wave for the Southern sites (wave 4) was 47 (Adimora et al., 2018). This age is near the end of the reproductive age range, limiting the likelihood that women would then become pregnant and have a live birth. Furthermore, setting geography aside, the women enrolled in the WIHS might not constitute a representative sample of WLWH. Instead, they may represent WLWH who adhere to the study's protocols and are likely to engage with HIV care.

Another limitation was that women self-reported their healthcare utilization behaviors, which may have led to recall and reporting bias. Furthermore, the frequency and nature of the WIHS questionnaires may have limited the data captured on retention in care in the current study since different questionnaires were used during different study periods. These differences were accounted for, as described in the methods section, but may still have affected the reported results. In addition, given the changes to clinical recommendations and participants' access to care over time, the inferences that could be made in the present study were limited for data spanning 17 years.

## Implications

#### **Research Implications**

The present study raises awareness of the possible downside to having rich longitudinal data with an outcome only secondarily captured through self-report questionnaires potentially subject to bias from memory and social desirability. Though viral suppression was accurately captured, there was no way to verify HIV care engagement as clinical records were not accessed. The reported retention in care in this sample was low; however, this was most likely due to the six-month intervals at which the questions were asked, as well as the visits during which no healthcare utilization questions were asked (visits 29–38). The results of the present analysis suggest that even in the absence of accurate HIV care engagement data, viral suppression—as assessed based on laboratory data—was low and did not improve over time. This supports the concept of HIV care as a continuum, where patients with HIV leave and reenter care, as well as

improve and deteriorate in terms of their viral suppression status. Further research is required to determine the predictors of long-term or stable retention, to optimize not only retention but also viral suppression.

Beyond this, more research is needed to examine retention and viral suppression in combination over time in terms of the proportions of retained and virally suppressed individuals versus other groups such as those retained but unsuppressed, not retained but suppressed, and not retained or suppressed. Retention was not found to have a protective effect on mortality, which was relatively low in this sample. Further research regarding the role of HIV care on outcomes such as mortality is required. In addition, engaging and disengaging with the HIV care continuum, as well as changes in viral suppression, should be assessed for a negative effect on the wellbeing of WLWH.

Maternal perinatal health has enormous consequences for the wellbeing of the mother. Although the WIHS provides a comprehensive and rich dataset with well-documented biological and behavioral data, there remain many critically important unanswered questions about timely and optimal follow-up postpartum for WLWH. Current evidence shows that WLWH often experience viral rebound postpartum, which can lead to viral resistance, sexual transmission to partners, disease progression, and increased maternal morbidity (Chen et al., 2019; Momplaisir et al., 2021; C. A. Swain et al., 2016).

Investigations comparing different care models of postpartum follow-up offer much promise for the future identification of underlying facilitators of and barriers to postpartum follow-up, and subsequent early identification, prevention, and appropriate treatment for women at risk of poor retention of care and lack of viral suppression. Although the ACOG guidelines suggest proper care coordination following delivery (McKinney et al., 2018), often WLWH encounter an even more fragmented care system between their HIV care, pre- and postnatal care, and pediatric care for their HIV-exposed infant(s) (Momplaisir, Storm, et al., 2018). Comparing systems with optimal versus poor follow-up can inform institutions on the best model for this vulnerable population.

Lastly, though it is generally known that there are substantial challenges in following up women living with HIV, those who receive a diagnosis during pregnancy are particularly at risk of failing to engage with follow-up. Phillips and colleagues (2018) found that being newly diagnosed with HIV was a significant predictor of disengagement in their sample of women from Cape Town, South Africa (Phillips et al., 2018). Future investigations using the WIHS dataset should compare the outcomes by the timing of diagnosis, to further contribute to the literature on how outcomes differ between those diagnosed before pregnancy versus during. Furthermore, WLWH should be aggressively recruited in their early reproductive years to see how they fare along the care continuum post-delivery.

## **Clinical Implications**

Patients from Southern sites performed better in terms of retention and viral suppression than those from non-Southern sites. Though the small sample limits the inferences that can be made about this, one important clinical implication is the possible benefit of recent recommendations regarding the care of WLWH and their care during the postpartum period. As previously stated, the recommendations made by ACOG regarding the postpartum period are recent. The Southern sites have been open for less than 10 years, and the engagement and viral suppression observed there suggest that these recommendations benefit women and protect them from poor outcomes. Accordingly, screening and emphasizing their proper care in the months immediately after delivery have implications for the long-term health of WLWH.

Finally, the present study identified low income and substance use to be significant factors associated with HIV-related mortality, suggesting the need to provide these demographic groups with further support. Although improving women's income levels and/or reducing their drug use is challenging, the results of the present and previous studies suggest that, with the right support and services, these challenges can be overcome. Though 120 participants—42% of the original sample of 283 women—were deceased and/or no longer participating in the WIHS after 10 years, the reported mortality rates were lower than expected. Yet, we have noted that the women in the WIHS represent WLWH who actively engage with the study protocol, rather than being representative of the overall population of WLWH, with potential implications for the research findings as a result. Looking ahead, by engaging in further, improved research work to better understand the factors that put women at risk, and accordingly, limit the influence of these factors to help them to meet their needs, postpartum WLWH's stable engagement with the HIV care continuum can be ensured, without interruptions to their care and the resulting poor outcomes.

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