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Integrating Mother and Child Influences into the Multilevel Factors Impacting Women's HIV Care Continuum Outcomes

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Master of Science
Georgia Southern University
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Abstract

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Background: In spite of recent declines in HIV rates among African American women, the burden is still skewed towards African American and Hispanic women between the ages of 15-39, especially in the southern United States.

Objective: The study aims to examine how maternal factors differ across defined care continuum groups and how multilevel interactions and contexts condition care engagement and adherence among women living with HIV.

Methods: We recruited 33 participants (96% African American, 4% other races) who were female by birth and between the ages of 25-60 years from the Atlanta WIHS for one-on-one in-depth interviews. Themes were evaluated using the Bronfenbrenner Socioecological Model and Berkman Model of Social Networks. Specifically, emergent themes were embedded into these two models in order to develop pathways by which care outcomes may vary by care group.

Results: Involvement of children with HIV care varied across care groups and influenced access to and maintenance of care. Pregnancy played a significant role in diagnosis and care engagement across all care groups. Participants reported modifying risky behaviors, such as drinking, as well as experiencing heightened anxiety during this period. Care engaged women seemed to have a higher perception of and access to care that optimized their safety and the safety of their neonate, aside from the indiscriminate focus on prevention of mother to child transmission. However, care detached women reported receiving care during pregnancy in a manner that suggests disengagement from the decision. In addition, reproductive counseling and referral contributed to women leaving care after diagnosis and never initiating care. Women's encounters with other hospital staff, including receptionists and social services, appeared as important to their participation in care. Timing of appointments and flexibility of the health care provider to accommodate other obligations (particularly those related to maternal duties) played a large role in retention in care. Although most of the care inconsistent and care detached women had a good outlook on life and some self-motivation, this did not translate to better care outcomes.

Conclusion: The results elicit the need for integration of reproductive and maternal needs into HIV care and treatment. Social interactions are an important component in the health of WLWH, especially among those of childbearing age. Further investigation is warranted among pregnant women to gain a deeper understanding of culturally appropriate methods of reproductive counseling. Results also suggest the need to investigate the impact of child outcomes on post-partum retention in care.

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CHAPTER 1: INTRODUCTION

Problem Definition and Justification

It is well established that the proportion of African American and Hispanic women living with HIV (WLWH), especially in the southern United States, has continued to rise with a primary proportion of these being women of childbearing age (ages 15-39). Understanding the interaction between HIV diagnoses and the distinguishing maternal factors that differentially influence care outcomes among women is important in order to address the current gaps in HIV medicine. Such understanding could extend our efforts at improving fetal and maternal outcomes in WLWH as well as enhance interventions that could counter current disparities.

Background

Until the mid-1990s, when there was a dramatic upsurge in incidence of HIV among women, research on HIV was focused on the male population [Bacon et al., 2005]. Despite advances in treatment and recent declines in HIV among women, a disproportionate number of African American and Hispanic women continue to be affected by HIV relative to other races/ethnicities [CDC, 2016]. The principle of social justice makes all people entitled to protection against threats and unnecessary harm. However, the presence of these ideals of fairness, more so in concept than in practice, contribute to significant discrimination experiences among WLWH, with African American women and those of Latino origin being more vulnerable [Aziz et al., 2011, Grant and Mortett et al., 2015]. According to UNAIDS, there are 3 million annual births among WLWH. This is significant in HIV medicine when considering the linkage of delayed entry to care, worse continuum of care outcomes, and the excess risk of mother to child transmission.

At the end of 2013, the U.S. Center for Disease Control and Prevention reported new HIV infection rates as high as 61% among Black/African American women [CDC, 2016]. Elevated vulnerability linked to high-risk social networks has been documented among African American women [Berkman et al., 2000, Fletcher et al., 2015]. It is crucial to understand how multi-dimensional factors shape and sustain the racial/ethnic differences in HIV acquisition and care outcomes.

In 2012, 87% of AIDS cases among females of childbearing age in the United States were attributed to heterosexual transmission [CDC, 2014]. The southern region of the United States has the highest AIDS prevalence in the country. A higher experience of institutionalized racism, stigma and discrimination in this region heightens the risk of HIV infection and vulnerability of WLWH [Fletcher et al., 2015]. These patterns are noteworthy, especially for women of childbearing age located in this region. The Metro Atlanta area, one of the top 10 Metropolitan cities in the United States, is home to more than 5.4 million residents. According to the U.S. Census Bureau, the proportion of U.S. Black/African Americans is about 34% while 54% are Black relative to 38.4% White in the Atlanta area. Historically, the racial distribution of resources in the United States have resulted in limited access to resources for racial/ethnic minorities. This skewed distribution of resources has led to a direct association between lower socioeconomic status and higher concentration of diseases and adverse health outcomes [Phelan, 2004].

African Americans exhibit excess mortality on every cause of death relative to Whites [Dressler, 2005]. Important structural-level health determinants, including poorer household quality and neighborhood services, limited access and lower quality of education, and poorer employment opportunities, have been reported for this population [Williams, 2013]. High levels of stress associated with the experience of discrimination, low job control, and social isolation are factors that influence negative mental and physical health outcomes among Black and Hispanic women relative to others races/ethnicities [Aziz et al., 2011]. Further, there is evidence associating racial stereotypes with quality of care and range of medical procedures prescribed in the health system [Dressler, 2005]. Delayed diagnosis, poor or infrequent treatment, inappropriate disease management, and denial of appropriate medical procedures is documented among Black women relative to Whites [Griffith, 2015, Williams, 2014]. These factors elevate the risk of acquisition of HIV infection among African American women, increases the "risk for delayed HIV diagnosis, delayed entry into HIV care, poorer treatment outcomes, and excess mortality" [Aziz et al., 2011].

Other individual level factors including poor mental and physical health are reported causes and or consequences of the living experiences among African American WLWH and are important in HIV prevention and treatment [Chae et al., 2010]. Associations between poor mental health, alcohol use, greater vulnerability to rape, and unwanted pregnancies have been reported among WLWH [Gilbert et al., 2015]. Links between health care experiences and continuance in care following big life events, such as pregnancy, are also important in understanding issues around increased risk for lesser care involvement among women [Cook et al., 2016].

A population's health exemplifies more than an intricately drawn model of risk factors and health status of its individual members. It represents a paradigm produced by mediating individual, interpersonal, and social factors and political institutions and policies [Satcher, 2010]. Historically, HIV intervention activities have focused on an individual's health behaviors and outcomes as separate entities from their social or environmental influences. Many of these approaches have been implemented with an unrealistic separation of ‘health experts’ from ‘others’. The outcome was externally driven interventions that were unmatched to needs and unsustainable.

Ironically, many of these interventions have produced and reproduced an unintended gap between ‘the haves and the have nots’, as they proffer solutions out of the reach of the poor. Consequently, in contrast to the increase in resources, higher levels of health inequities have resulted [Gostin, 2012]. Thus, a deeper understanding of the mechanisms that lead to the inextricable associations between these factors and health outcomes, beyond acknowledging them as ‘confounders’, is very crucial.

Care Continuum

Within the cascade of prevention of mother to child transmission (PMTC), several steps have been implemented to reduce the transmission of HIV infection to unborn infants. Consequentially, important terms such as ‘linkage to care’, ‘care initiation’, ‘retention in care’, and ‘ART adherence’ have been developed and discussed in the research. Adherence to care has been identified as a critical determinant of positive outcomes in HIV-positive people, and retention in care has been used as a proxy indicator of this factor.

Several studies have been carried out to determine factors that impact HIV care and management. These studies include adherence in rural South Eastern US populations [Boehme et al., 2013], retention and viral suppression in African American women [Blank et al., 2015], barriers and facilitators to retention in care [Kempf et al., 2010], individual and contextual factors affecting ART initiation, adherence, and retention for HIV-infected pregnant and postpartum women [Hodgson et al., 2014], retention in care among pregnant and breastfeeding

HIV-Infected women [Rollins et al., 2014], and retention strategies and factors associated with missed visits among low income women at increased risk in the U.S. [Haley et al., 2014]. Despite continuous use of the term retention in care in the monitoring and implementation of HIV programs and policies, there is no standard definition. However, the core for this term is continuous or ongoing engagement in HIV care when and where it is most crucial. [Rollins et al., 2014].

Despite being an important predictor of care, measuring a general sense of continuity as against observing discrete time frames result in missed opportunities for interventions in HIV care and treatment. Most studies utilize two or more visits in 12 months following baseline as a predictor of retention in care [Haley et al., 2014, Rollins et al., 2014, Blank et al., 2015]. However, this approach risks loss of tracking coverage of patterns of missed hospital visits and other data that may differ along a fine gradient of the care continuum.

Study Purpose

Several research and interventions have aimed to reduce the prevalence of HIV/AIDS and understand the facilitators and barriers to care among WLWH. However, most of these have concentrated primarily on PMCT, conception decisions, and pregnancy outcomes. Deeper understanding of factors that influence maternal response to care and treatment and how such factors vary across context is essential to inform future interventions targeted at this population. Characterizing the influences of motherhood and the maternal/child related processes that act as antecedents to the differences observed in care outcomes among defined care groups could also be important in filling knowledge gaps in the reproductive health of WLWH. Such understanding could extend our efforts at creating tailored interventions that are well prioritized to improve maternal and fetal health outcomes in WLWH [Rollins et al., 2014].

A qualitative study is appropriate to explore and recognize salient nuances and variations in engagement in care among discrete care groups of WLWH. The knowledge of how identified facilitators and barriers may interact with maternal factors to impact treatment across defined care gradient is critical in HIV medicine.

Research Questions

The study will answer the following questions:

1) How is care engagement and adherence among WLWH conditioned by multi-level interactions and contexts?
2) How do the influences of maternal factors differ across a defined gradient of the care continuum?

CHAPTER 2: LITERATURE REVIEW

In the U.S., women of childbearing age are experiencing an increasing burden of HIV, constituting 25% of recently diagnosed HIV infections [Boehme et al., 2014]. Many studies related to women's drug use and HIV prevention have established that social inequalities, including gender imbalances and power inequity, have exacerbated drug use and diseases such as AIDS among women [Phillips et al., 2009]. The fundamental factors of drug use and disease burden are further compounded by other social inequalities associated with race/ethnicity, sex, and other social factors [Phillips et al., 2009]. Consequently, in the light of these broader social issues, African Americans are exposed to multiple group-specific burdens that may have consequences on their health seeking attitudes [Phillips et al., 2009].

Relative to other women in the U.S., African American women and their Hispanic counterparts experience a disproportionate burden of HIV [Blackstock et al., 2015]. Of the total women diagnosed with HIV in 2011, African American women had a new infection rate of 64% compared to 18% among Whites and 15% among Hispanic/Latina women [Center for Disease Control and Prevention, 2013]. This represents a rate approximately 19 times higher than that of White women and about 4 times the rate seen among Hispanic women [Fletcher et al., 2015]. In 2014, African American women made up 62% of newly diagnosed U.S. cases, representing a slight decline in infection rate [CDC, 2016].

Across the globe, access to antiretroviral therapy (ART) has greatly increased and subsequently reduced the rates of new infections [Chaiyachati et al., 2014, Fletcher et al., 2015]. In addition, effective ART has significantly reduced the morbidity and mortality associated with HIV infection [Holtzman et al., 2015]. While these advances have encouraged HIV-infected mothers to pursue motherhood, much of the research has focused on the health of the unborn child and minimizing of perinatal transmission from mother to child rather than the health of the expectant mother [Boehme et al., 2014, Loutfy et al., 2012].

In spite of evidence that ART is as effective in women as men, WLWH have a higher rate of HIV-related morbidity and mortality compared to men [Kempf et al., 2010, Greig et al., 2014]. Studies have attributed this discrepancy to differential engagement in care and adherence patterns and behaviors, among other factors [Chaiyachati et al., 2014, Greig et al., 2014]. Maternal health is a strong determinant of the risk of mother-to-child HIV transmission (MTCT), with a range of 15-30% that can be reduced to <2% if well managed [Ezeanolue et al., 2015]. Maternal variables such as viral load, mode of delivery, and postpartum breastfeeding practices are critical in determining infant outcomes [Kreitchmann et al., 2012]. However, prenatal and postnatal retention in care and/or treatment adherence have documented impacts on care outcomes. Long term positive outcomes, as defined by the US National HIV/AIDS strategy (NHAS), include "reducing new infections, improving health outcomes, and reducing health disparities" [Holtzman et al., 2015]. High rates of medication adherence have been reported in pregnant women followed by several missed appointments and non-adherence to medication postpartum. [Kempf et al., 2010]. A deeper study and understanding of the factors that influence maternal response to treatment and how such factors vary across context is essential to inform future interventions targeted at this population of interest.

Theoretical Model

Many individual, behavioral, and social level factors have been used to conceptualize and expound the greater disease vulnerabilities in women. However, to effectively understand the interactions of women with HIV/AIDS and the relationship of race to HIV morbidity and mortality, and effectively propose multi-level effective interventions, a multidimensional, multilevel, integrative theory is key [Krieger, 2001]. “The ecological perspective calls for an independent, multidimensional, multilevel, interactional view of the etiology of individual or community health” [Grzywacz et al., 2014]. This theoretical framework encourages us to think critically about the interconnections between factors that predict HIV infections among women It also allows us to recognize how individual behaviors are influenced by individual characteristics as well as multiple environmental features.

Using the Bronfenbrenner Socioecological Model (SEM), this study sought to understand how care engagement and adherence among women can be conditioned by multilevel conditions/contexts and influence outcomes disproportionately. SEMs recognize how the interactions of a range of multilevel factors play a crucial role in determining public health. Although differing in their approaches, SEMs have motivated a research pool on the correlation between persons, the environment, and health behaviors. They show how public health has evolved from the epidemiological foundation of causation focused on individuals to a new, holistic view of origins and impacts [Fairchild et al., 2010].

Bronfenbrenner sets the stage for understanding how the quality and context of the environment can influence HIV vulnerabilities in women. Bronfenbrenner ecological framework describes how development and behavior is influenced and varied by the different environment in which humans exist throughout their lifespan. The model recognizes the impact of a multiple range of influences including the most proximal factors such as immediate family, interacting mesofactors such as neighborhood and distal factors such as Federal policies on the development of an individual. The individual, microsystem, mesosystem, exosystem and macrosystem are structures within which we can fit and conceptualize mediating roles of the environment on women and HIV/AIDS infection [Nelson and Keith, 1990]. The Bronfenbrenner model represented in (Figure 1) can be expanded to describe how variations accumulate across care groups among women living with HIV.

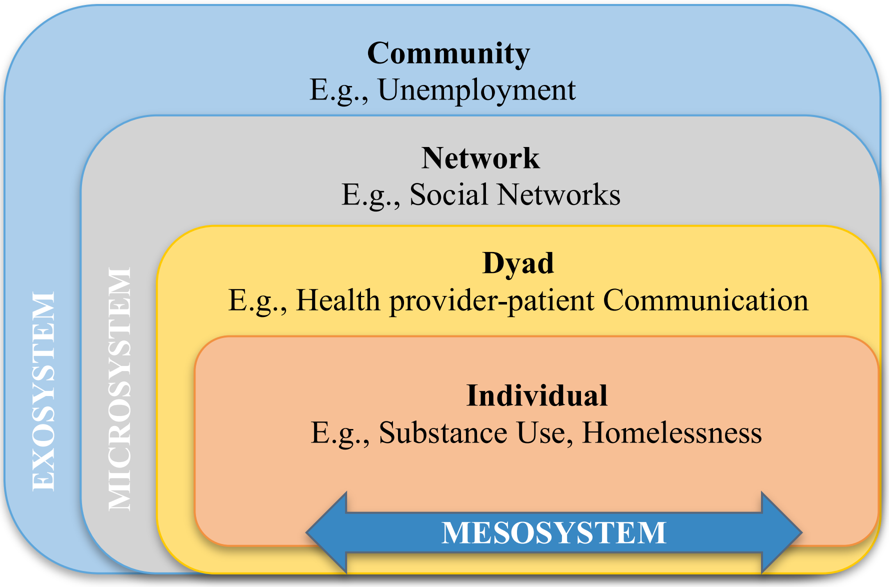

Figure 1. Bronfrenbrenner Model of HIV Care Outcomes

Health Issues of WLWH

Identifying factors that influence maternal care among WLWH has become critical in understanding the inequalities that women face. Previous literature have discussed these issues under several headings including Individual and Interpersonal factors [Hodgson et al., 2014], Patient factors, Health Care Environment and External Environment [Holtzman et al., 2015], Facilitators and Barriers [Boehme et al., 2014, Kempf et al., 2010], and Predisposing Factors, Enabling Factors, and Needs [Hodgson et al., 2014]. These factors have been classified as follows: 1) Individual Factors, 2) Interpersonal factors and 3) Structural Factors

Individual Factors

Individual factors include those inherent to a woman, which could either be within her control (e.g., her personal willingness to stay healthy (self-motivation)) or outside of her control and consciousness (e.g. knowledge of ART).

Sociodemographics. Several behavioral, biological, and structural pathways link age, education, and gender with engagement in care. Age (in years) has been associated with initiation and adherence with care. In a study focused on care retention, increase in age was associated with a higher likelihood of being retained in care [Blank et al., 2015]. Conversely some studies have reported an increase in age associated with a lower level of care seeking among women. This difference was associated with responsibilities and other factors related with age [Hodgson et al., 2014].

Low education attainment is associated with increased risk for and vulnerability to HIV/AIDS infection and mortality in women. In addition to lowering the perception of risk due to poor access to information, it also impacts care seeking behavior. Dependence on spouses for preventive actions, difficulties understanding treatment instructions, and implications of non-compliance are documented among women with lower education attainment [Felix and Ceolim, 2012].

Multiple studies have identified gender inequalities and sexism as having dire, harmful implications for health outcomes in women. Gender based violence (GBV) is a predisposing factor as well as a consequence of HIV; further, GBV is a major contributor to ill health among women [Diaz et al., 2001, Dunkle and Decker, 2012]. GBV, a significant risk to women that limits their control within relationships, reduces their ability to negotiate for safer sexual practices and increases vulnerability to multiple sexually transmitted infections as well as unwanted pregnancies [Diaz et al., 2001]. It also contributes to a range of health problems, including physical injuries, depression and suicidal tendencies, and poor adherence to medications post infection [Dunkle and Decker, 2012].

Fears Related to HIV and Motherhood. There is increasing documentation of an increase in the desire to have children and decision to become pregnant among WLWH. This increase has been influenced by the development of Highly Active Antiretroviral Therapy (HAART). However, evidence of inadequate knowledge about pregnancy has been reported among WLWH who desire to have children [Jones et al., 2013, Clouse et al., 2014, Loutfy et al., 2016]. This inadequate knowledge could be a major factor influencing the high proportion of ~50-83% unintended pregnancy among WLWH [Loutfy et al., 2016]. The psychosocial stress related to the knowledge of unintended pregnancies, fear of and guilt for mother to child transmission, and concerns related to negative impact of HIV on their children plays a critical role in care engagement among these women relative to women who have planned pregnancies [Fletcher et al., 2015, Loutfy et al., 2016].

In addition, having a child under the age of 18 years old has been associated with a lesser degree of care engagement among women. The ability for a woman to focus on and follow up with care is impacted by having a child under the age of 18 and the time and cost of child care needs [Blank et al., 2015]. Some studies have shown that a mother's perception that care for their infants and young ones surpassing her own is a major barrier to care engagement [Clouse, 2014].

On the contrary, women's desire to protect their unborn children, and to live for their family members, has been positively associated with increased care engagement in some studies [Fletcher et al., 2015]. In studies conducted in Nigeria and the U.S., women's desire to nurture their family members was identified as an enabler for care engagement [Hodgson et al., 2015]. In contrast, the fear of losing family members (e.g., spouse) due to accidental disclosure from attending clinic visits negatively impacts care seeking attitudes among women [Boehme et al., 2015].

Lifestyle Demands. The essential demands of a job and other lifestyle practicalities may be either an enabler or barrier to care in women, dependent on the specific factor [Clouse et al., 2014]. Successful engagement in and continuation of care can be impeded by practical issues like schedule conflicts. Unwillingness to call out of work for several reasons, including fear of disclosure, working full time with low benefits, financial constraints, and other operational reasons like access to the health facility from stable housing and work, have huge consequences on a woman's level of care participation [Blank et al., 2015].

Homelessness, lack of food, misplaced medications, difficulty swallowing medication, confusion about medication regimens, and mobility demands are more major determinants of lack of retention in care [Boehme et al., 2015]. Lack of food was especially important in studies in Kenya, Tanzania, and South Africa. The negative side effects associated with taking medication on an empty stomach inhibits medication adherence [Hodgson et al., 2014].

Substance Use. A growing body of evidence has shown linkages between women who abuse drugs and an increased susceptibility to sexual abuse from non-intimate partners, including drug dealers, and other behavioral and biological risks associated with HIV infection [Gilbert et al., 2015].

Significant differences in linkage to care and engagement in care has been established among alcohol and drug users and non-users in several U.S. studies [Hodgson et al., 2015]. Non-users have better retention in care when compared with illicit drug and alcohol users. This may be related to an observed interaction of violence among women with substance use disorders and AIDS; this is referred to as the Substance Abuse, Violence, and AIDS (SAVA) epidemic. [Gilbert et al., 2015]. Women who visit substance-using venues, such as bars and clubs, have an increased risk for aggressive sexual behaviors, particularly when judgment is impaired due to drug use [Holtzman et al., 2015]. Further, periods of substance abuse has been reported to elevate feelings of health apathy in patients, resulting in several missed visits and poor engagement with care [Holtzman et al., 2015].

Interpersonal Factors

There are several complex interconnected factors that could be enablers or barriers. These factors are influenced by the woman and other relationships in her life [Hodgson et al., 2015].

Faith, Spirituality, and Religion. Earlier research in Kenya identified religious experiences as a major multi-direction factor underlying retention in care. Religious beliefs, attendance of over-night meetings, and camps are major factors that unfavorably impact adherence [Wachira et al., 2012, Hodgson et al., 2015,]. Religious beliefs are also a strong predictor of pregnancy desire and intention among women and couples living with HIV [Akelo et al.,2015].

Studies done around Thai culture, which is primarily centered in Buddhism, show that most of the Thai values potentially expose women to increased risk of infection.

Although Buddhism legalizes the practice of monogamy, it fosters social acceptability of prostitution and creates gender imbalances that limit women's access to healthy choices (e.g., negotiation of sexual practices). The culture describes an ideal woman as one who is submissive and defers to her husband in all things, while the ideal man can engage in uninhibited sexual escapades [Klunkin and Greenwood, 2005]. This inferior status of females increases Thai women's vulnerability to infections.

Previous work among Hispanics has also shown that a lack of spirituality may be critical to initiation and maintenance of sexually risky behaviors. Strong spirituality encourages coping mechanisms among the infected. Spirituality has proven to be a buffer of negative consequences among HIV-infected. Spiritual access, support, a feeling of community, and other important elements of faith seem to play critical roles in preventing new infections as well as increasing care seeking attitudes and survival [Loue, 2006].

Disclosure status. Studies have identified non-disclosure as a major determinant of engagement in care among WLWH [Clouse et al., 2014]. While disclosure can act as a coping facilitator, it can also expose an already vulnerable population to social stress associated with stigma and discrimination [Vyavaharkar et al., 2011].

In general, disclosure rates are much higher among Whites compared with African Americans [Vyavaharkar et al., 2011]. This is especially important because secrecy of care engagement and non-involvement of a partner are deterrents to continuing in care. Non-disclosure is commonly attributed to fear of abandonment by an intimate partner, the perception of stigma and discrimination following disclosure of status, and the fear of being accused of unfaithfulness. In addition to partners, non-disclosure to family members and friends makes receiving and adhering to care very difficult. This results in several skipped visits, hiding medications, skipping medication doses, and other deliberate efforts to avoid rousing suspicions concerning their HIV status. The fear of accidental disclosure due to the geographic location of hospitals and care facilities further contributes to social isolation and avoidant coping among HIV-infected women [Vyavaharkar et al., 2011, Tam et al., 2015].

Studies among pregnant and post-partum women in Sub-Saharan Africa identified disclosure as primarily associated with individual factors including younger age, lower level of internalized stigma, higher level of education, and lower level of avoidant coping among others [Tam et al., 2015].

Social Support. Many studies have reported the buffering role of social support among WLWH. Studies exploring the association between social support, perceived social support, and medication adherence among HIV-infected African American women have highlighted the importance of both social support factors on health outcomes [Vyavaharkar et al., 2011]. Family functioning, the interactions between the immediate family, has been found to be a major determinant of support and a mediator of stress in HIV-positive African American women [Robbins and Szapocznik, 2003]. These studies provide evidence that HIV-infected African American women are frequently confronted with conflicts and exclusions from important familial relationships following HIV status disclosure. Lack of support has a more profound impact on non-disclosure, social withdrawal, isolation, and non-adherence for females than for males [Robbins and Szapocznik, 2003].

Relationship turbulence, feelings of being unloved and uncared for, stigma, and an HIV-infected partner are negatively associated with medication adherence in HIV-infected women. [Edwards, 2006]. There is also evidence of an inverse association between social support and adverse psychological situations (e.g., depression) in WLWH. Emotional support and support satisfaction fosters a range of positive outcomes in WLWH [Edwards, 2006, Vyavaharkar et al., 2011].

Structural Factors

Structural factors fall outside of the sphere of control and agency of the woman. They include the broader environment, such as political and legal factors, that influence care engagement and adherence.

Access to Health Services. Securing inexpensive and dependable transportation to appointments is a frequently identified facilitator for utilization of HIV care for many patients. Long distances to medical facilities, traffic, scheduling inconsistencies, and the strain on financial resources associated with free transportation services (when available) make transportation a barrier to care for many patients [Kempf et al., 2010, Boehme et al., 2014, Holtzman et al., 2015]. Globally, inclement weather and conflicts with appointment times and work hours are major barriers to accessing health services. This consequently results in inconsistent care engagement [Hodgson et al., 2014, Johnson et al., 2015].

Studies conducted in the Nyanza province of Kenya provided the insight that improving HIV care by providing ART access can modify the use of health services [Ackers et al., 2013]. Morles-Aleman and Sutton (2014) showed that, despite higher rates of new HIV infection among Hispanic populations living in the southern U.S., the majority of this population has less access to care than non-Hispanic Whites. Stigma, immigration issues, and a lack of Spanish-speaking health providers were identified barriers to seeking health care among this group.

Interactions with Health Workers. Studies report that health workers' attitudes and the perception of their attitudes by patients influence women's adequate engagement in HIV care [Magnus et al., 2013, Boehme et al., 2014]. Perceptions of stigma, other negative attitudes (e.g., poor communication), and quality and quantity of interactions that were perceived as judgmental were barriers to ART initiation and retention in care [Clouse et al., 2014, Hodgson et al., 2014]. A study conducted in Louisiana found that women and older patients may be more susceptible to perceiving and internalizing stigma in the HIV health care environment [Magnus et al., 2013].

Positive, non-judgmental attitudes perceived by patients as a provider’s willingness to care, “warmth”, and “seeing a friendly face” were enablers for ART adherence in a study of HIV-infected women in the Southeastern U.S. [Kempf et al., 2010, Hodgson et al., 2014].

In a study from Philadelphia, positive provider attitudes were described by patients as “trust, compassion, delivery of individualized care, and responsiveness” [Holtzman et al., 2015]. This was exemplified by the equal and respectful treatment shown to patients, interest in engaging in quality conversations and interactions, addressing questions and concerns clearly, phone call responses, and follow up. Patients confirmed that all of these provider actions fostered trust and a good interaction that supported engagement in care [De et al., 2012, Holtzman et al., 2015].

Supportive social interactions with health care providers have also been found to have an inverse relationship with depression [Vyavaharkar et al., 2011]. This relationship may play a critical role in decreasing one’s risk of depression. Further, it may be an important resource to improve self-efficacy and self-esteem in WLWH [Vyavaharkar et al., 2011]

Clinic Factors. Dealing with complicated scheduling and clinic routines can impact the likelihood of care engagement [Holtzman et al., 2015]. Scheduling challenges due to competing life activities, limited appointment openings which makes getting desired appointment time difficult, missed refill dates, complex automated phone systems, long clinic waits, and unprofessional attitudes in the healthcare centers are among the factors that dissuade patients from engaging in care [Boehme et al., 2015, Holtzman et al., 2015].

Previous Interventions

There is an urgent need to increase engagement in care among women, and previous interventions do not close the gaps of the racial/ethnic disparities in care. Concentration on the reproductive health of WLWH has led to interventions targeted at preconception, which includes providing access to counseling and handling referrals. However, gaps in knowledge have been reported among families despite regular visits with a health professional [Ndlovu et al., 2009]. Other interventions targeted at prevention of MTCT have resulting in the creation of several guidelines for management and administration of ART, breast feeding, and other preventive strategies.

Clinical trials addressing the increased incidence of preeclampsia and higher risk of gestational diabetes among WLWH relative to the general population have been conducted to assess the interaction between maternal health and continuous use of ART in pregnancy. While preventing transmission and progression of HIV, provider-endorsed cessation of ART in favor of broader maternal health has been reported in the UK [Loutfy et al., 2016]. Despite contradictory data about risk factors linked with these diseases, policies and guidelines regarding one-year cessations of ART have been implemented [Loutfy et al., 2016].

Although most of these interventions have been targeted at reducing the prevalence of HIV/AIDS, many have concentrated primarily on the health of the unborn child rather than the overall health of the child and mother. Understanding how overall maternal health – cessation of treatments, stigma, access to optimal reproductive care, optimal methods of nursing infants, and the impact of raising children without a partner – may affect willingness and readiness to continue in care postpartum is important in guiding policies and future interventions. Further, characterizing the impact and roles children play along the continuum of care is important to fill knowledge gaps in the reproductive health of WLWH.

Theory and Justification for Qualitative Study

An integrated approach to health is one that is created by an awareness of socially constructed realities and an emphasis on the role of the "non-expert" in creating knowledge and action. There are many factors that impact successes and challenges in engagement in care in the HIV care continuum. Common themes previously reported include race, self-efficacy, individual, interpersonal and structural factors. However, there is the need to further explore how these factors may impact engagement in care along discrete categories of the care continuum. It is also important to know how these factors interact with reproductive and maternal health among vulnerable populations.

Results of previous quantitative studies have revealed varying incidence rates between women of childbearing age and other age groups. Associations have also been established between age and stage of motherhood, age of children, and care involvement among women. In addition, there is compelling evidence linking higher risk of perinatal depression with WLWH and lower engagement in care [Loutfy et al., 2016]. However, qualitative research can provide in-depth and complimentary information to these quantitative findings, providing insight into how and why maternal and reproductive factors affect engagement in care along a defined care continuum.

The socioecological perspective of health makes obvious the inherent limits of implementing health programs without focusing on prevailing influences or context. A comprehensive insight into individuals' perspectives and attitudes, and how the interconnectedness between these factors may affect continuation in care, is best matched to qualitative in-depth interviews. As part of the Women's Interagency HIV Study (WIHS), we can analyze qualitative in-depth interviews in order to explore and understand how maternal factors impact engagement in care in defined care groups.

Using Grounded Theory methodology, this study will explore maternal facilitators and barriers to care engagement. The knowledge of how HIV affects women over time has been reported in a lot of qualitative studies; however, there is still a need to explore how the interconnection between HIV and motherhood affects African American women care involvement. Such studies are warranted in order to create effective interventions, as treatment options and health outcomes are modified over time. It is important to create contextually appropriate interventions as the childbearing structures (e.g., age at first child birth) change with time and geographical location. Understanding the relationship between the rights and access to reproductive health care among WLWH and overall health can help inform strategic collaborations and interventions in the population of interest.

CHAPTER 3: METHODS

This research is a qualitative substudy of 33 women from Atlanta WIHS, a larger long-standing study focused on understanding the impact of HIV infection on a cohort of HIV-positive women in the U.S. Qualitative interviews were conducted by the team of investigators and project staff to explore and understand how individual and contextual factors impacted engagement in care in the HIV care groups defined for this study. The team also examined the broader spectrum of HIV vulnerabilities associated with maternal and reproductive health and the development of interventions around observed facilitators and barriers to engaging in care.

Research Design

This study employed a qualitative research approach, collecting data through in-depth interviews. The Principal Investigator employed a Grounded Theory design to get the lived experiences of the respondents and obtain an expanded perspective of maternal determinants, barriers, and facilitators of care among WLWH on their path to HIV care and management.

Grounded Theory involves an inductive and deductive process that enhances understanding of previous observations with new insight and focus. This was used to provide insights into how and why maternal factors affect engagement in care along a defined care continuum. The resulting process offered a meaningful guide to generate suitable interventions.

Population and Sample

The participants in the study were WLWH recruited in two stages from the Atlanta WIHS. Respondents were included if they had received an HIV diagnosis and were female by birth, between the ages 25-60 years, and residents of Atlanta.

For the purpose of this study, the women were divided into 3 broad care groups based on where they fell in the HIV care continuum, including newly diagnosed, linked to care, and care compliant. They were grouped as “care engaged”, “care inconsistent”, or “care detached”. Care engaged was defined by attendance of more than 2 provider visits in the past year, routine CD4/Viral Load (VL) lab tests, and adherence to ART. Care inconsistent was defined by attendance of at least one provider visit in the past year and at least one CD4/VL test after diagnosis. Care detached was defined by no routine care of any form after initial diagnosis. Ethics and research approval was obtained from Emory IRB.

Sampling and Recruitment

Purposive sampling was conducted among WLWH enrolled in Atlanta WIHS. This method of sampling was used in order to ensure representativeness of race/ethnicity, age/developmental stages, and inclusiveness of experiences across the HIV care continuum. The women were mostly African American (African American, 94%, other race, 6%) who were diverse in their care experience. Recruitment methods allowed for participants with a range of care experience, which included newly diagnosed women, women engaged with care, and care compliant.

Instruments and Procedures

For the one-on-one in-depth interviews, an interview guide was developed in order to ensure consistency in the conversations and produce reliable data. Each interview was administered face to face by either the Principal Investigator or a trained staff interviewer in a private venue. The overarching goal of the interview was to generate data that addressed barriers and facilitators of care as well as develop possible interventions adapted to the study population. Interviews were between 60 and 90 minutes in length.

Questions in the guide addressed issues including circumstances surrounding HIV infection, maternal profile, disclosure of HIV status, presence and use of support factors, clinic or provider relationship, perception of stigma, knowledge of HIV care and adherence, reasons for non-adherence, and barriers to care. Sample questions included:

To understand Testing History:

A1: Tell me about your history with HIV. How did you find out? Why did you get tested? Where did you get tested?

A1a. Had you ever been tested before that? Why or why not?

To understand HIV/AIDS Treatment, Knowledge, Attitudes, and Practice:

B1. Let's talk about treatment and care for HIV/AIDS; what does HIV/AIDS care mean to you? Types of medications? Doctor's visits? Alternative therapy?

B2. How important is it for you to know lab values - information about your blood cells and about the virus? Why or why not?

B3. How important is it for you to go to a doctor or nurse regularly? Why or why not?

B4. Do you currently take any antiretroviral medicine or HIV medications?

For those who currently take any antiretroviral medicine or HIV medications:

B5. Tell me more about your experience with taking HIV medications and the care you've received.

B5a. Tell me about the medications you are currently taking.

B5b. Some people experience side effects from the medication. How has that been for you?

B5c. Do you have any other problems with taking your medications? Like trouble swallowing pills or any other issues?

B5d. Do you always take your pills exactly the way your doctor or nurse tells you to take them? Like the number of pills, the time of day, things like that?

B5e. How often does your doctor or nurse ask you questions like this about your medications?

B5f. What helps you to stay on your medications? What makes it hard?

B5g. Has there ever been a time when you were NOT in treatment for HIV? Tell me more about that time. How many times did you go off treatment? Why did you go off?

B5h. Do you think HIV treatment and care is helping you? Why?

For those who currently do not take any antiretroviral medicine or HIV medications:

B6. I understand you are not taking HIV medications right now. Can you tell me more about that? Cost? State of mind? Feelings about your clinic or provider? Anything else?

B6a. Have you ever taken HIV medications in the past?

IF NO: Have you ever talked to a doctor or nurse about taking HIV medications? Tell me about that conversation.

IF YES: Tell me more about that time. When did you start/stop? Why did you start/stop? What medications were you taking? Did they help?

B6b. Do you think HIV medications would help you? Why?

B7. Do you see a doctor or nurse for your HIV treatment and care?

For those who say YES:

B7a. In the past 6 months, have you missed an appointment with your doctor or nurse? Why?

B7b. How hard is it to make those visits? What would make it easier? Is transportation an issue? Childcare? Employment

To understand General Health Problems and Medical Events:

D2. Have you ever been pregnant? What were the outcomes of the pregnancy or pregnancies? Do you currently have children?

IF YES: Were you living with HIV at that time? Have these events affected your HIV treatment and care? How so?

To understand the influences of Social Support:

E1. Now we're going to discuss telling other people about your HIV status. Tell me about your experience with telling people like family or friends about your HIV status. Who have you been able to tell? What was their reaction like? Were you expecting that reaction?

E2. Are there people you have chosen NOT to tell about your HIV status? Why or why not?

The last section of the guide focused on giving the participants time to make final comments about issues that may not have been addressed in the interview. All interviews were audio recorded and transcribed verbatim.

Transcript Coding and Analysis

Initial data analysis involved reading the transcripts verbatim, identifying important words or group of words, and labeling, describing, and comparing emergent themes that could be supported with the data in hand.

Using the raw data collected, the emerging themes and categories were reviewed, elaborated on, and used in an iterative yet systematic manner to develop the codebook. Transcripts were coded using NVivo 10.

Axial coding allowed the comparison of relationships and interconnection of codes to groups as well as group to group. Related codes were grouped into categories, and descriptive sub-codes (e.g. social/emotional support; support with HIV treatment and care and children) were generated for each category until saturation was achieved. Saturation was achieved when the newly collected data only generated codes that fit into previously existent categories.

Structural Coding

Structural coding was done using NVivo 10. It allowed study staff to assess all the responses to a particular question with an assigned structural code.

Advanced Systematic Qualitative Analysis

Advanced systematic coding and analysis was done on a number of randomly selected transcripts. This process involved comparison of experiences, experience to codes, and looking for the interrelationships between codes, among codes, and categories as well as comparing categories to categories.

Constant comparative analysis of data is a critical part of the inductive process that grounded theories are built on. The process is the basis for building models that can be supported by the generated data. This ongoing, successive analysis ensured continuous refining of the codebook and integration of new themes into it until all the data had been collected and a fully cohesive theory emerged.

Transcript Sub-sample Enumeration

Thirty percent of the one-on-one interviews were randomly selected for advanced coding and analysis.

Intercoder Reliability (ICR)

Double coding of transcripts was performed to assess the reliability of codes. ICR rates were calculated by NVivo 10 throughout the coding process. Transcripts that generated values lower than 0.80 were selected for review and reconciliation.

CHAPTER 4: RESULTS

Participant Characteristics

The sample included a range of women at different points in the HIV care continuum. All participant care characteristics and demographic information were collected by linking their interviews to their WIHS participant numbers. In this sample, 31(94%) of the 33 women in our study were Black/African American. This is comparable to the distribution of African American Women in the larger cohort. In-depth interviews were conducted among all 33 women. The median age of interview participants was 48 years old. All participants had been previously screened for eligibility before enrollment in the study.

Overview of Qualitative Findings

Three main themes emerged from the in-depth interviews. These main themes were social support factors, structural factors, and individual factors. These themes show the relationships between maternal and reproductive roles and the barriers and facilitators African American women may experience with care engagement. The explorative research yielded sub-themes (e.g., housing) that described similar patterns of risk for sub-optimal care outcomes. Further, multi-directional themes (e.g., involvement of children in care) emerged. With evidences of multilevel maternal variables (e.g. age of child at mother's diagnosis influencing HIV care priority), the study examined reproductive gaps and needs in the HIV care continuum, using conceptual structures and established behavioral models.

Structural Factors

This theme sought to explore structural factors that were crucial determinants of care engagement among African American women of reproductive age. Several different subthemes emerged, including housing, reproductive counseling, and hospital staff (friendliness and flexibility of staff, inconvenient hours/process for medical care/medication pick-up).

Housing and Housing Support

Housing and housing support, which could also be linked to social isolation, were explored among the three defined care groups (Table 1).

> *"I missed it a couple times because I was outdoors I ain't have nowhere to stay, but now I got a permanent place to stay and I go every month" – Group 1*
>
> *"Housing support, let me tell you housing support sucks here in Georgia…I probably would have relapsed cause I ain't have no place to live" – Group 2*
>
> *"Yeah all the housing is not good…they put you in a drug environment." – Group 3*

Table 1. Influence of Housing on Care (n=33)

Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Housing	*"I: Have you ever missed any?"* *"P31: ...So me figuring out me physically and health wise is probably just going to fall in there somewhere as other things now that our housing is stable. It's been stable for a few months"*	*"PI01: I've asked for help with housing. I was told no because it was considered as double dipping…the government already got me in subsidized housing when I went and signed where me and my son live over there, but I said I want to let my son continue to stay there. He's 24…I want my own place and the only way they was going to help me is if I was willing to stay in a boarding house..."*	*"I: : housing you mean?"* *"P21: yeah all the housing is not good... they put you in a drug environment."*

Reproductive Counseling

Reproductive counseling explored the extent to which pre-birth diagnosis, care and counseling during pregnancy influenced care perception and engagement, especially among women who were diagnosed during their reproductive years (Table 2).

> *"I: um so have you ever, had you ever been tested before that one time*
> *P34: um yeah I have four children and I was tested with each and every one of them….I'm from Illinois and they test during pregnancy." – Group 1*
>
> *"like four months later I got pregnant with my son by someone else. So of course um AID Atlanta the health clinic there said that I couldn't stay there because I was pregnant and they were trying to send me to Grady IDP. I didn't know what IDP was at the time. I just said no I don't want to go there. So I said I'll find my own doctor"- Group 2*

Table 2. Influence of Reproductive Counseling on Care (n=33)

	Quote		
Theme	**Group 1**	**Group 2**	**Group 3**
\Reproductive counseling (Testing or diagnosis pre-birth)	*"I: what, with all that you was- all this other stuff that was going on how did you still make It where you were still taking your medicine regularly?* *P33: Basically…my doctors when I was pregnant were like the coolest..."* *"I: Ok. And then you mentioned the other healthcare that you have.* *P14: Well care for planning for healthy babies…no you cannot be pregnant to get on that plan…that gives me um, I think that gives me a sign of encouragement to keep going…it's expanded health care yeah."*	*"P24: so she basically, she came in the room, she had a consent form, was like here's the consent form for you to get your tubes clipped, tied and burned. I was like you know, I was like cause I'm like I'm only 27. It seem like it wasn't an option like you need to get this done…* *"P32: …I' m like if, if I'm out and I see a mother breastfeeding I think I'm never going to be able to do that you know. I can have a child but I can't breastfeed my child."*	*"P19: I found out that I was pregnant and I also found out I was HIV positive…it didn't really dawn on me when they first told me…until about maybe 5 or 6 years later it came across my mind again.* *I: So when you received your diagnosis did they put you on any medication?* *P19: No"*

Staff Friendliness. This subtheme sought to understand how provider-participant relationship, which can also be linked with social interactions, was associated with care engagement (Table 3).

> *"I love Dr. (name). He is just the cat's meow. He has a passion for what he's doing and its infectious…That speaks to the level of trust I have for him because he does they know-everybody knows what they're doing you know...cause they know" – Group 1*
>
> *"It wasn't the doctor it was the social service and the, the, the I guess the triage nurse or whatever to get to the doctor. I mean the cruelty and the ugly stuff and their behavior. So after a while you get tired of that I mean I don't have to travel this far for somebody to treat me- ill treatment" – Group 2*

Table 3. Influence of Hospital Staff on Care (n=33)

Sub Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Hospital staff \\Unfriendly/ rude	*"I: How often does your doctor or nurse ask you questions like this about your meds?* *P4: How often, um- all the time, every visit."* *"P6: "Um I like my doctors. There's a nurse there that I really like us..She's really nice…Like if I call her on her voicemail and say I'm out of refills or whatever she gets it done..."*	*"I: Does your doctor ever talk to you like this? Does she ask you these kinds of questions about taking your meds this way?* *P26: No"* *"I: no conversation no-?* *P24: Yeah, like no help, you know it was so cold to me..."* *I: So you discussed how your Doctor, was telling you how to stick on your meds...* *P7: And he asks every visit I mean-…I had a real good doctor it was just some of the people before you get to your doctor. It's that just really turned me off..."*	*"P21: Still not great because the doctor's you know, they- they can't deal with more than one thing at one time…and it's important that you have that kind of relationship with your doctor where you can tell them anything and they will cut you off and a lot of times you never even discuss what you needed to discuss with them."*

Flexibility of Staff. This subtheme explored accommodation of absences and rescheduling, including practical maternal responsibilities and experiences (Table 4).

> *"I can call him on his office phone. I can call him on his cell phone. If I have questions about anything, anywhere, anytime- he absolutely is 100% authentic in his answers" – Group 1*
>
> *"Um well my doctor um probably…she was like you're doing so good. She's like I don't need to see you every three months anymore. So they set my appointments like five to six months out now" – Group 2*

Table 4. Influence of Flexibility of Staff on Care (n=33)

Sub Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Hospital staff \\Flexible hospital staff	*"P34: So when it comes to my appointments I actually do a lot of- a lot of grouping. Um when it comes to Dr. (name) actually anything I have to do at IDP if they fall within the same week if I haven't already while I was there coordinated them, I will call and email and get them all into one day"*	*"P7: cause they know I'm taking care of my mom too, um had to call them and you know they was – well can you come in later or the next day. So basically it ain't you missing an appointment...because they will call you and ask you if you know you missed this appointment you know afterwards"*	*"P21: I had to get rid of one provider. The first provider I had there I had to get rid of her because she wasn't, she was not helping me get my social security so I could get somewhere to live and I was on the streets and around drug people and I- I needed the doctor's help."*

Care process. This subtheme explored how the processes and procedures involved in the care of women can impact their response to care. The procedures seem to differ sharply among the patients in each care group (Table 5). The difference between the processes involved in the care of women in Group 1 is more obvious.

> *"I: So, what helps you keep all your doctor's visits?*
>
> *P: Um, that there- the time that they are- once every four months isn't hard"- Group 2*

Table 5. Hours/Process for Medical Care (n=33)

Theme	Quote		
	Group 1	**Group 2**	**Group 3**
\ Hours/process for medical care/medication pick-up	*P17: "No I don't have a wait there, they don't- I don't wait..."* *I: So you are in and out pretty quickly?* *P17: Yes. Yeah every time, every time"*	*"I: Is there anything else that you don't like about what you currently have for HIV care?* *P18:...but I think everything should happen within a reasonable amount of time you know what I'm saying. I feel like if I have an appointment at 2:00 to do labs I should be seen at 2:00"* *"I: Do you experience long wait times then?* *P18: Sometimes"*	*"I: And it took two years to get the medical reports?* *P21: Yes I had to get um proof of residence, I had to get proof of unemployment, proof of social security, proof of everything… you got an appointment at 1:00 it will take you to 4:00 to see the doctor. The process there is just too long"*

Social Factors

There were four main facets of social factors, including involvement of children with HIV Care, influence of motherhood on care, child care support, and fear of HIV affecting maternal roles (Table 6-9). This major theme sought to understand how interpersonal maternal experiences may influence and vary among women of childbearing age engaged in care. They provided insight into the mediating mechanisms of the association between social isolation among women of childbearing age and care engagement. Participants discussed how their engagement with each of these factors impacted their care across the three defined categories of the care continuum.

Involvement of Children with HIV Care

This theme sought to understand the social relationship between women and their children post-diagnosis, particularly the impact of the involvement of children on care engagement (Table 6). It also sought to capture how the characteristics of children may differ across care groups. Involvement of children with HIV care was a powerful facilitator to entering and maintaining care.

> *"P2: My son he get um- when he wasn't, when he wasn't sick he had his own apartment. I stayed with him. He went with me to the hospital. He knew all about my health and he keep me- you know" – Group 1*
>
> *"P31: she was 12 years old…And she's, and I mean even her and her father they make sure that I take my medicine" - Group 1*
>
> *"I: So what really is helping you to stay on the medication?*
> *P26: My wanting to live longer. I want to live longer…My-he was more supportive to me than my son was cause my son was still angry"- Group 2*

Children's (<18 years) willingness to be involved with and connected to the mother's care process post-diagnosis appeared to motivate and support the mother's care engagement. For example:

> *"She was 12 years old…And she's, and I mean even her and her father they make sure that I take my medicine" – Group 1*

The absence of children who were of age (≥18) as well as the intentional or unintentional absence of support from children who were old enough to be involved with care was deterrent to HIV care.

> *"So I was like ok what's really going on and my kids at the time were three and four and I just didn't know a whole lot about the disease just seeing people dying" – Group 2*
>
> *"I: your kids- how did they respond to this whole situation when you're in the hospital?*
> *P: Um, um- I don't know. It was like you know what I really can't say..." – Group 3*

Table 6. Influence of the Involvement of Children on Care (n=33)

Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Involvement of children with HIV care	*"I: Ok alright so what else has helped you stay in care and treatment this whole time? P3: My daughter…Oh she's, she – she is so concerned about me… Mommy are you sure you're ok? Are you sure you're healthy?"*	*"P24: After the initial diagnosis...I was very depressed um, and my daughter wasn't living with me at the time..." "P11: I done got sick so don't nobody want to take care of me, but I said it's all good"*	*"I: What about your kids - how did they respond to this whole situation when you're in the hospital? P23: I don't know. It was like you know what I really can't say..."*

Motherhood

This theme encompassed the perception of women about motherhood, the maternal demands of children post-diagnosis, and how a life event such as pregnancy influenced engagement with care (Table 7).

In all three care groups, many of the mothers – especially those with younger children – experience conflicting interest in their maternal duties and confront a need to prioritize self-care versus child care.

> *"I: Some of the women we've been talking to said that it's kind of hard to balance um their own appointments with their kids' appointment.*
> *P20: Well it is and it ain't because they only go to the doctor once a year…um they only go to the doctor once or twice a year that's it and I go all the time so" – Group 1*
>
> *"You know I got really exhausted um and then dealing with my daughter it kind of took a toll on me and then my body started changing with the stress" – Group 2*

Pregnancy plays a significant role in care engagement across all groups. Changes associated with this life event including gagging, morning sickness during pregnancy, changes in care regimen, and behavioral risk modification are reported across all the groups.

> *"…but when I wasn't pregnant I would drink alcohol sometimes, but I can't now because of the baby." – Group 1*
>
> *"It was so bad...I have morning sickness throughout the pregnancy it's not just for the first trimester. It was throughout the pregnancy so I couldn't even keep the medicine down" – Group 2*
>
> *"I: Ok so that's what kind of made you start when you, when you got out of um prison you ended up getting pregnant?*
> *P29: They wanted – take care of me when I was pregnant, when I was pregnant, but they also wanted me to take care of my HIV so they sent me here." – Group 3*

Table 7. Influence of Motherhood on Care (n=33)

Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Motherhood\ Influence of motherhood on care	*"I: Was it because you cared about yourself of you kind of was like I got to do it for the baby or both?* *P33: For both…"* *"I: And then tell me more about your experience with taking HIV meds and any care that you receive.* *P6: I think my experience has been ok till this morning ironically enough I was getting ready to take it and I kind of gagged and I threw up a lot, but I don't know if that's because I'm pregnant or what because that's never happened before"*	*"I: What has been like stand out awesome versus those that may not be?"* *P15: You know I got really exhausted um and then dealing with my daughter it kind of took a toll on me and then my body started changing with the stress"*	*"I: Now when you were pregnant they didn't put you on anything?"* *P19: Yeah they put me on AZT while I was pregnant. Once I had my baby they took me off the AZT."*

Fear of HIV affecting Maternal Roles

This theme encompassed how HIV management can be inhibited by fears of losing the benefits associated with receiving and providing maternal support (Table 8). The study explored the relationship between fear, denial, and a woman's involvement with care as well as how the age of woman's children at birth influenced care.

The fear of maternal roles being affected by HIV was commonly observed across all care groups. The women expected that disclosing their status would put them at risk for isolation and separation from giving and receiving maternal care.

> *"I haven't told my kids…I just don't feel as though I don't want to be isolated. I know, you know when people find out its ugh- you know and I don't want to be isolated so – for that purpose I won't tell anybody right now" – Group 1*
>
> *"I still want her to see me as her daughter that's it. I don't want her to see me as anything else" – Group 2*

Table 8. Fear of HIV affecting Maternal Roles (n=33)

Sub Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Fear of HIV affecting maternal roles	*"P3:...but like damn how am I going to tell my daughter?"*	*"I: So you haven't told your mother and why is that?* *P18: I still want her to see me as her daughter that's it. I don't want her to see me as anything else"*	*"I: So you were with this guy for 8 or 9 years and she's running around?* *P23: Yeah"* *"I: And you finally said mom I need you to take her?* *P23: Yeah, yeah-yeah..."*

Child Care Support System

This theme sought to understand perception of support for maternal roles and how disparities in receiving this support could influence engagement in care. The negative consequences of the fear associated with losing the desired involvement with maternal responsibilities was buffered by a system of child care (Table 9).

> *"Um I do have a pretty good support system as far as the younger two. You know the lad that keeps them if I needed her to get them because an appointment interfered she would without a doubt." – Group 1*
>
> ***"**So um they been watching the kids for me and my mom she picks them up on Wednesdays" – Group 2*

Table 9. Child Care Support System (n=33)

Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Child care support system	*"I: um if you had to prioritize getting to an appointment for something else, like how high rating priority for – for going to doctor appointments ten being the most important, zero being not important at all. What would you give it? P34: The kids activities…Um I do have a pretty good support system as far as the younger two. You know the lad that keeps them if I needed her to get them because an appointment interfered she would without a doubt."*	*"P24: So um they been watching the kids for me and my mom she picks them up on Wednesdays"*	*"I: So you were with this guy for 8 or 9 years and she's running around P23: yeah I: and you finally said mom I need you to take her? P23: Yeah, yeah-yeah um.."*

Individual Factors

These factors included the associations between mental health and the woman's self-motivation, outlook on life, and guilt/perception of HIV's effects on child/guardian's health.

Mental Health

This theme sought to explore the interconnection between the woman's mental health and their reproductive health and the care engagement (Table 10). Subthemes included self-motivation, outlook on life, and guilt or perception of HIV status on child/guardian's health.

Table 10. Mental Health (n=33)

Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\Mental Health	*"I: so in terms of mental health and counseling…what makes it helpful?"* *"P3: You know and then being a single mom um, my daughter has, is growing and has gone through different phases and different changes ...you know just dealing with that..."*	*"P7: A couple of them I felt like I wasn't getting nothing out of, I think I was doing more- getting them more counsel then they were giving me so"*	*"I: So, so they gave you these medications what happened with the medications? You started taking them?* *P21: Ok but then the mental parts kicked in because they were sending me through all these changes and I wasn't getting no help, no support and nobody- you know you telling me to do all this but you're not listening to the fact that I don't have any means any way to do this… it was just you know mental, you know not being uh stable and you know you can't keep appointments, you can't – it's just destruction."*

Self-Motivation. This subtheme addressed how a woman's personal drive to get care is related to her care engagement (Table 11).

> *"It's not hard at all considering that if I don't go what the outcome will be. No. I would go no matter what.* ***If*** *I have to come from a different state I'm going to go. If I have to walk here from New Mexico I'm going to go." – Group 1*
>
> *"I take my life, I take my body very seriously." – Group 2*
>
> *"The same thing you know but you got to want this for you you can't want it for your daughter, your children, you can't want it for your mom, you got to want it. Then it take work." – Group 3*

Table 11. Influence of Self-Motivation on Care (n=33)

Sub Theme	**Quote**		
	Group 1	**Group 2**	**Group 3**
\\Self-motivation	*"I: Not, not- she's not a support for you in any other part of it.* *P16: I just figured you know everything happens for a reason. I need to be a – I need to be a testimony for somebody else to help somebody else not make the mistakes that I made"* *"I: Is that fair to describe that that's what has helped you stay healthy and on course?"* *"P22: That's the main thing, I had to get it in my mind ok you're sick and you got to take this medicine, you got to go to these doctors you got to exercise you got to..."*	*"I: Why is it that you've made pretty much all of your appointments?* *P26: Not really. I encourage myself... I got it made up in my mind that this is what I want and this is what I really, really need most of all in my life I need this first. I need this first, I need my treatment first."* *"P1: I had to take control of the situation. I can't just go and say...woe is me...It's not going to work, it's not going to keep me alive"*	*"I: Women will take medicine while their pregnant cause you kind of got to, what made you keep, did you keep on after?* *P29: the reason why I started taking my meds, I didn't just want to exist I wanted to live life"*

Outlook on Life. This subtheme captured the likelihood for a woman to be engaged in care based on how she perceived life as a whole. Negative outlooks on life potentially made a woman unwilling to live and consequentially uninvolved or less involved with care (Table 12).

> *"I thank God for who I am and how I am because I realize that everybody is not, this journey has not been easy" – Group 1*
>
> *"I was heard other people's stories saying that it didn't have to be a death sentence and I decided that I wanted to live" – Group 2*
>
> *"I still feel normal, like normal people. I am still normal, just living with the diagnosis that I can't change, you know" – Group 3*

Table 12. Outlook on Life (n=33)

Sub Theme	Quote		
	Group 1	**Group 2**	**Group 3**
\\Outlook on life	*"P3: I thought about you know going into nursing school and oh maybe I'll get my masters in public health and the more I become involved in this and the more I feel what's going on from a physiological perspective…I was just telling (name) the other day uh I think I'm going to go to PE school. Yeah I know right. (Laughs)"*	*"P15: I'm gonna do anything that I can to help the physicians and the doctors and the pharmaceuticals, figure out what better they can do to give us a long life span cause that's really what we want. A normal, happy, long life span."*	*"P19: I still feel normal, like normal people. I am still normal, just living with the diagnosis that I can't change, you know"*

Guilt of HIV Status affecting Child/Guardian's Health. This factor was both a motivation to be involved in care, particularly for pregnant and nursing mothers, and a deterrent of care, particularly for women who have HIV-positive children (Table 13). This effect varied across care continuum groups.

> *"I: He's still got his own challenges though, do you think those challenges are related to your status? P: Might be… I won't know until I – I know I can't get him evaluated (inaudible) by Grady's…" – Group 1*
>
> *"you know I didn't want to tell her so she wouldn't get sick worrying about me so I just kept it and, but when my heart was having some issues and I had to keep going to the doctor and they thought I had a- well they diagnosed me with a form of heart failure and then they said the neuropathy and whatnot so- I you know went ahead, just went ahead and told my mom because I didn't know what, what would happen to me." – Group 2*
>
> *"I remember she started having seizures, the doctor said that the news I gave her about me being HIV positive stressed her out so bad and made her start having seizures" – Group 3*

Table 13. Guilt of HIV Status (n=33)

Sub Theme	**Quote**		
	Group 1	Group 2	Group 3
\\Guilt/ perception of HIV affecting child'/ guardian's health	*"P2: He's still got his own challenges though,* *I: Do you think those challenges are related to your status?"* *"P2: Might be… I won't know until I – I know I can't get him evaluated (inaudible) by Grady's..."*	*"P15: That's probably been the worse experience I've had with my daughter going in to the pool and they told us to get out. my daughter cried and cried.. I felt that if I would have just pursued this and sued them .. it'd have been real negative and kind of uncomfortable where I lived and I didn't want my daughter to experience anything uncomfortable so I just stood quiet you know, just never used the pool"*	*"I: How do you think she acquired it?"* *"P23: She was 16 when...Oh well she lived a wild lifestyle as well. Uh she was on drugs too.. And how she got it she-she did whatever she wanted to do. I dropped her off with my mom house, over to her grandma house."*

Comprehensive understanding of these themes and their impact on care status using existing models provide ample opportunity to improve care outcomes among WLWH.

CHAPTER 5: DISCUSSION

Findings

Conducting fertility-related research that encompasses pre- and post-conception experiences among WLWH, an already marginalized and highly vulnerable population, may help address the current gaps in HIV care among these women. The results of this study show that individual, social, and structural factors are not mutually exclusive but essentially interrelated. It also elicits the integration of reproductive and maternal needs into HIV care and treatment. To analyze the gaps in research among vulnerable women post-partum, we identified subthemes within the care continuum.

Involvement of children with HIV care increased access to and maintenance of care in the care engaged group (Group 1). Also, a good number of the care inconsistent women (Group 2) showed a history of good social interaction with their children after HIV diagnosis. This improvement could be due to the children's ability to seek care knowledge, promote health behaviors in their mothers, and positively demand better and consistent care of their mothers. Age of child when mother is diagnosed is a well-documented factor in the mother's care engagement [Phillips et al., 2014, Phillips et al., 2015]. However, it is noteworthy that the teenage children (<18 years) of the care engaged women provided as much support as those ≥18 years old.

Trends in the care inconsistent (Group 2) and care detached women (Group 3) suggest that age of children may not be the only crucial factor affecting maternal care. Other issues such as the geographical proximity of women to their children post-diagnosis, relationships of children and mothers post-diagnosis, and children's willingness to be involved in care are essential factors in this pathway. This indicates that it may be essential to assess and address social integration and support from children among vulnerable WLWH.

According to Fletcher and colleagues (2015), motherhood is one of the easily affordable social identities in which marginalized women can find solace. This profound sense of social responsibility may explain why many of the mothers in all three care groups, especially those with younger children, experience conflicting interests and must confront the need to prioritize self-care versus child care. Their willingness to take care of themselves is enhanced by having children's support. Availability of children's support was a facilitator, allowing women to prioritize their care and treatment as needed. In addition to facilitating uptake of care by resolving conflicts in maternal duties and self-care, the presence of children's support also served as a buffer to the effects of the stress associated with having children <18 years.

Pregnancy plays a significant role in care engagement across all care groups. This life event seems to positively heighten the woman's concern for her health and safety. Many women reported modifying some of their risky behaviors, such as drinking, during this period. However, there is also an increase in anxiety associated with changes due to pregnancy, such as gagging, morning sickness, and change in care regimen. The perception of motherhood as a social need may encourage many of these women to seek care. There seemed to be a perception of HIV care as a complementary and non-substitutionary responsibility among pregnant women in the care consistent group relative to other groups. This suggests that women who are care engaged may have more perception of and access to care that optimizes their safety as well as that of their neonate aside from the indiscriminate focus on prevention of MTCT.

The care detached women reported receiving care during pregnancy in a manner that suggests they were disengaged from the decision. Their care involvement seemed to be a social responsibility towards their infants or someone else. This is observed in the use of phrases like "they wanted me to [get or remain in care]". The lack of engagement in care observed among care detached women suggests that the social necessity of motherhood could be modified by structural factors; further, social influence could either facilitate or serve as a barrier to receiving care post-partum among WLWH.

As suggested in recent literature, pregnancy as a life event seems to facilitate care seeking attitudes among women [Berkman et al., 2000]. However, it raises concerns within mothers about safety and the progression of HIV. This could be associated with the inability to keep medicines down, stress associated with morning sickness, and the increased risk of transmission to their neonate. In addition, the absence of the power to negotiate a care regimen as well as potential negative outcomes for the infant are huge barriers that could result in reduced engagement in care post-partum.

The fear of maternal roles being affected by HIV was commonly observed across all care groups. This fear is closely linked with non-disclosure of status and acts as a strong barrier to care engagement. Women expected that disclosing their status would put them at risk for isolation and separation from giving and receiving maternal care.

As previously discussed, several studies have proposed the central importance of structural factors on care engagement among women. The absence of housing served as a major barrier to engagement in care across all care groups. In addition, housing played a critical role in defining the structure of social networks and the degree of bonding and similarity within these networks. These housing factors were critical in the health behavioral pathways of women. Housing involved modifying risk-seeking behaviors, such as drug and alcohol use and patterns of engagement in care.

There was a strong association between services available and the extent to which women were willing to be involved with care for the care engaged women. Many of the pregnant women became aware of their HIV status while conducting a pregnancy test. The absence of or the form of reproductive counseling and referral contributed to women leaving care after diagnosis and never initiating care. This suggests that it is critical to have targeted intervention for both WLWH and their health care providers. Previous studies support the need to target women who are newly diagnosed during pregnancy, as they may be more vulnerable to care disengagement [Phillips et al., 2014, Buchberg et al., 2015, Phillips et al., 2015].

As earlier suggested, the mother's willingness to receive care post-partum could be a product of the transitioning experiences between conception and delivery. This willingness is a strong determinant of the outcomes of children born to WLWH [Phillips et al., 2014]. Most of the care inconsistent and care detached women reported having demeaning health care experiences. Interactions with health care providers for both those who had intended and unintended pregnancies played a major role in care initiation and retention. However, it was observed that these demeaning experiences were not isolated to doctors. Women's encounters with other hospital staff, including the receptionist and social services, appeared as important to their participation in care. Many of the care engaged women reported having systematic follow up to missed appointments. Such personal efforts by health providers seem to enhance trusting relationships between health care providers and their patients.

Timing of appointments as well as the flexibility of the health care provider to accommodate roles (particularly those related to maternal duties) played a large role in retention in care. The ability for women to coordinate their appointments to fit with those of their children, or other people for whom they were responsible, was a common need across all three care groups. Long waits for test results and appointments and other care protocols were also commonly aired as a major barrier to engagement in care. Job demands, maternal duties, and other self-needs may account for the lower tolerance for such long waits during care.

Individual factors play a critical role in the ability of the patient to see a need for services. An essential component in this is one's mental health. The mental health of many of the women in each care group was compromised. However, a majority of the care engaged and care inconsistent women were being treated for mental health issues. This treatment is critical, as unstable mental health could encourage an inability to follow a health regimen. The mental health of women is also an important factor in correctly evaluating their satisfaction with care; their care satisfaction definitely impacts optimization of care. There was a strong interconnection between mental health and behavioral attitudes (e.g., drug and alcohol use), which has a large impact on care.

Women's general outlook on life and their self-motivation spoke to how women across each group related to life and were personally motivated to seek care. Even though most of the care inconsistent and care detached women had a good outlook on life and some self-motivation, this did not translate to better care outcomes. This finding suggests that individual mental health factors, although very crucial, do not overcome the significant structural and social factors discussed above.

Theoretical Framework

The themes that emerged from the study, map well onto the Bronfenbrenner conceptual model. Thematic analyses showed that social interactions and relationships are of particular importance for understanding barriers and facilitators to care among highly vulnerable, childbearing age WLWH. Therefore, it became necessary to understand the underlying factors of varying health outcomes among the care groups using the Berkman model of social networks. Berkman's integrated framework posits a cascading process by which social contexts are framed and how these contexts translate to health outcomes (Berkman et al., 2000). In order to do this, the emergent themes were embedded into a combined model in order to suggest possible pathways by which care outcomes may vary by care group. The resulting model (Figure 2) was structured from the understanding of the relationship between these two models and the integration of critical components of observed themes into the models.

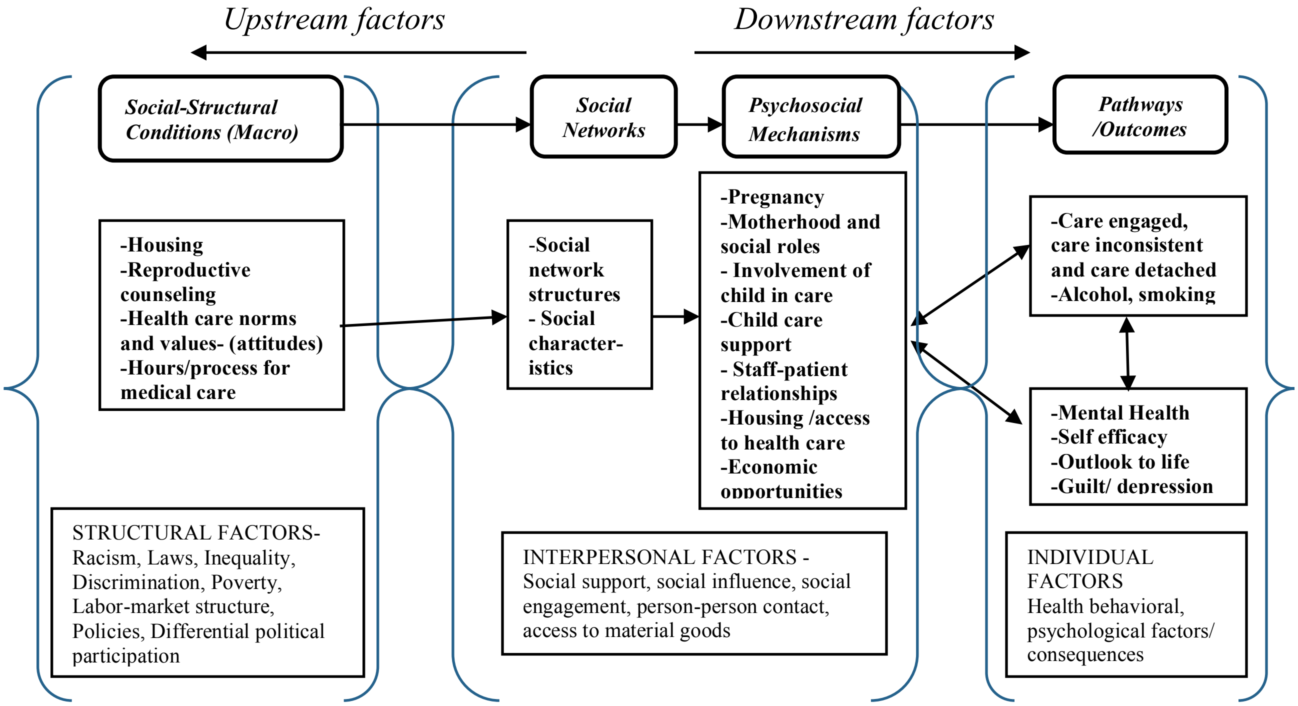

Figure 2. A conceptualization of the combined Berkman-Bronfenbrenner Model on HIV Care Outcomes among WLWH

Strengths. Utilizing exploratory qualitative research, this study probed the interaction between reproductive and maternal factors and barriers and facilitators that Black/African American women encounter when seeking and engaging in HIV care. The study also enhanced current knowledge surrounding maternal HIV care and involvement of children in the HIV care process. In addition, the study provided a theoretical advancement, utilizing a combined theoretical framework, with both the Bronfenbrenner socioecologic framework and Berkman model of social interactions, to describe the link between individual, social, and structural factors that act as either facilitators or barriers to care.

Limitations. This study may be limited by its use of purposive sampling among mostly African American women residing in the southern U.S. who were already involved in an ongoing study. This sampling strategy may have influenced and conditioned women's responses to some of the questions asked. In addition, social desirability and fear of losing benefits may have introduced bias. Sampling from the southern U.S., where racism is an additional contextual factor for an already vulnerable population, may prevent the generalizability to other states and contexts with different social experiences. Finally, the small proportion of pregnant women in each care group may limit generalizability of these findings to all pregnant WLWH.

CHAPTER 6: IMPLICATIONS AND RECOMMENDATIONS

Conclusions

This study successfully explored how facilitators and barriers to care significantly interact with reproductive and maternal roles among highly vulnerable WLWH. The data gathered from this study can be used to inform frameworks for future studies involving engagement in care and guide interventions among African American women of childbearing age. Targeted efforts should focus on situating neonatal outcomes alongside post-partum care as integrated outcomes of maternal HIV care to increase the likelihood of better care outcomes.

This study adds to the growing evidence of the need to focus on WLWH as individuals with reproductive and health rights rather than disease vectors [Ndlovu et al., 2009, Buchberg et al., 2015]. The preceding analyses have established that social interactions are an important component in the health of WLWH, especially among those of childbearing age [Kanniappan et al., 2008]. Some established barriers, such as stigma, were not discussed since the focus of this study was proximate maternal barriers and facilitators.

Recommendations

Several recommendations and proposals for future research emerged from this study.

1. An in-depth study around the impacts of the experience of pregnancy as a life event in its entirety, including aspects of fetal outcomes, among WLWH.

Addressing reproductive and maternal needs and increasing positive social interactions at the individual, social, and structural levels may enhance uptake of care among marginalized WLWH [Johnston et al., 2013]. The high number of unintended pregnancies and a general increase in desire for pregnancy among women and couples infected with HIV makes it necessary to conduct more studies among pregnant WLWH [Jones et al., 2013]. It also suggests the need to carry out more studies to understand how child outcomes could impact post-partum retention in care. Understanding how these outcomes could facilitate or deter care engagement may enhance the understanding of the effectiveness and interactions of drug regimens with pregnancy and consequentially lower MTCT rates.

2. The provision of culturally appropriate reproductive counseling and referrals for WLWH.

Healthcare experiences, including concerns associated with health insurance, are an important barrier to HIV testing among African American women. Education among healthcare providers and other hospital staff could improve the delivery of services to WLWH. There is also a need for more evidence-based knowledge of reproductive counseling methods, education, and recommendations for WLWH [Montgomery et al., 2003]. Integrating the social needs of these women into their healthcare routines may play a critical role in retaining women in care post-partum. Policies that strengthen the integration of reproductive and HIV care, such as integrated pregnancy/HIV diagnostic tests alongside STD treatments and HIV care, may be an effective forum to initiate awareness and interventions for this group. Having such supportive counseling environments may be critical for care retention and reduction of MTCT among WLWH.

3. The integration of educational interventions targeted at children, especially for those living in highly stigmatized communities.

Creating interventions that identify with cultural and social needs of motherhood and safe post-partum outcomes could contribute to enhancing positive social support, social influence, and social engagement that positively impact care. The understanding that children can positively influence care engagement can be utilized to tailor education interventions that are targeted at children >12 years in marginalized and highly vulnerable populations. Creating the capacity to provide support for women within such vulnerable groups by empowering their children, as well as involving them as peer educators in such a capacity, may have broader impacts.

Community-based participatory research has been shown to yield better results than individually targeted efforts [Pettifor et al., 1999]. Such community-based interventions could lessen the stigma associated with HIV as well as provide leverage to introduce trans-generational interventions built on the knowledge of the children and adults affected by HIV in these groups [Pettifor et al., 1999]. This could also play a critical role in enhancing the mental health status of women living within such marginalized communities.

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