

THE MEANING AND UNDERSTANDING OF UNINTENDED PREGNANCY: A  
QUALITATIVE STUDY OF PREGNANCY AMONG AFRICAN AMERICAN  
WOMEN LIVING WITH HIV

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## ABSTRACT

Few studies explore the phenomenon of unintended pregnancy among women living with the Human Immunodeficiency Virus (HIV). To decrease mother-to-child transmission and transmission to a sexual partner, contraceptive methods, cultural beliefs, in addition to protocols pertaining to preconception, pregnancy, labor, delivery and the postpartum period among women living with HIV must be considered. Half of the pregnancies that occur among HIV-positive women are unintended and requires monitoring and additional prenatal care to reduce adverse health outcomes. This qualitative study sought to increase knowledge of the meaning and understanding of unintended pregnancy among a sample of twelve urban HIV-seropositive African American women. Women shared their experiences related to pregnancy, risk and living with HIV. Many of the participants reported they experienced an unintended pregnancy, discussed lapses in contraception use, possessed knowledge of pregnancy and antiretrovirals, vertical transmission of the virus, sexual risk, and differences in adherence to antiretrovirals during and after pregnancy. Guided by grounded theory the major themes that emerged were used to develop a model that explained unintended pregnancy among the participants. The major themes included resilience, disclosure, and an instinct to protect. Additionally, culture, stigma, social support, contraception, and partner safety were secondary themes. This review suggests that a model of unintended pregnancy containing social-ecological aspects can describe predictors of pregnancy and potential prevention strategies. Furthermore, the future exploration of the challenges that African American women living with HIV experience with unintended pregnancies, efforts to manage their condition and prepare for a pregnancy are needed.

## DEDICATION

This dissertation is dedicated to my beloved “unc-pa”, Carl Meredith. This would be an amazing moment to share. I will always appreciate his love, kindness, encouragement and even his silence. I also dedicate my dissertation work to the first activist and trailblazers in my life, Eleathia and Miss Rocky. I can still feel their strength, boldness and wisdom. A special feeling of gratitude to my dear Aunt Roslyn, for without her I would not have known these beautiful souls nor found my passion.

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## Definitions of Key Terminology

**Attitude-** way of thinking or feeling that is reflected in a person's behavior

**Axial Coding-** process of relating codes, categories and concepts to each other through a combination of inductive and deductive thinking

**Birth control-** the use of any methods or devices to prevent pregnancy

**Contraception-** the use of artificial methods or techniques to prevent pregnancy during sexual intercourse

**Culture-** characteristics and knowledge of a particular group of people

**Disclosure-** act of revealing new or secret information

**Epistemology-** a study of understanding and knowledge

**Grounded Theory-** a systematic methodology involving the development of a theory and a specific method to gathering and analyzing data

**Human Immunodeficiency Virus (HIV)-** a virus that attacks the immune system and can lead to acquired immunodeficiency syndrome

**Mother-to-Child Transmission-** spread of HIV from a woman with HIV to her child during pregnancy, childbirth, or breastfeeding

**Open Coding-** labeling concepts, defining and developing categories from narratives

**Pre-exposure prophylaxis (PrEP)-** use of anti-HIV medications to keep HIV negative people from becoming infected

**Pregnancy Outcomes-** results of pregnancy, such as sex ratio, birth weight, spontaneous abortion, congenital malformations, lower birth weight, etc.

**Pregnancy-** the condition or period of being pregnant

**Resilience-** an ability to recover from or adjust to various conditions and circumstances

**Selective Coding-** final stage of data analysis where core concepts emerging from the coded data categories and subcategories have been identified through open and/or axial coding

**Stigma-** negative attitudes and beliefs about a person based on their condition

**Support System-** a network of people and/or resources that provide practical or emotional backing

**Unintended Pregnancy-** a pregnancy that is mistimed, unplanned and/or unwanted

## CHAPTER 1: INTRODUCTION

### Introduction

This chapter provides an overview of the purpose and focus of the research conducted explaining why the topic is one of importance and significance. The problem statement, statement of purpose, research questions, rationale and significance, my role as the researcher, and assumptions will be provided.

### Focus of Research

There are more than one million people living with HIV in the US; 280,000 are women living with HIV, many were infected through heterosexual contact during their reproductive years (Centers for Disease Control and Prevention, 2016). In contrast to the state of medical technology that was available more than 30 years ago, today women living with HIV can become pregnant with minimal risk of perinatal HIV and costly procedures. Approximately 8,500 women living with HIV give birth yearly (CDC, 2016). Since 2016, the number of children diagnosed with HIV acquired through perinatal transmission was reduced by 41% (Bankole et al., 2014; Centers for Disease Control and Prevention, 2019).

This reduction can be attributed to HIV testing during pregnancy and pregnant women adhering to antiretroviral medication. Prevention of unintended pregnancies among HIV-positive women is a strategy for preventing mother-to-child transmission (PMTCT) of HIV recommended by health organizations (World Health Organization, 2007, 2011). While intentional pregnancies among HIV-positive and negative women (Warren, Abuya, & Askew, 2013), men who desire a child (Lindberg & Kost, 2014), and serodiscordant couples (Brown & Zafer, 2018) have received considerable attention; very

little is known about unintended pregnancies, particularly among African American women living with HIV. Moreover, the literature is barren of narratives and analysis of the unintended pregnancy experiences of African American living with HIV.

This study explores the meaning and understanding of unintended pregnancy among urban African American women living with HIV. Specifically, the research explored the beliefs, attitudes and behaviors regarding unintended pregnancy, the influences of unintended pregnancy, social supports and the effect of HIV infection and unintended pregnancies have on the lives of urban African American women.

### Problem Statement

Addressing the problem of mother-to-child transmission of HIV is a global public health concern (Blake, Kiely, Gard, El-Mohandes, El-Khorazaty, et al., 2007; Gruskin, Firestone, Maccarthy, & Ferguson, 2008; Hussey, Nikolsko-Rzhevskyy, & Walker, 2014; Lampe, Smith, Anderson, Edwards, & Nesheim, 2011; Squires et al., 2011). More than 8,500 women living with HIV give birth yearly (Centers for Disease Control and Prevention, 2016a). Additionally, an estimated 25% of HIV-infected women express a desire to become pregnant after an HIV diagnosis (Craft, Delaney, Bautista, & Serovich, 2007); this does not conclude that women are actively planning. Research on women living with HIV having access to contraception, antiretroviral therapies, and prenatal care has increased in the last decade, while behavioral interventions focusing on their pregnancy decision making remain limited. Moreover, the literature has not fared well in terms of understanding cultural, sociodemographic, and social environmental factors affecting pregnancy decision making among women living with HIV. Not surprisingly,

the attention to unintended pregnancy and pregnancy has largely focuses on adolescent females (Macutkiewicz & MacBeth, 2017).

There are a disproportionate number of African American women living with HIV and receiving a HIV diagnosis (Centers for Disease Control and Prevention, 2017a). Upon diagnosis, women, as with the general population, are encouraged to begin medical treatment and adhere to their treatment regimen. HIV management requires lifelong treatment, several annual medical appointments, and effective communication with health care providers (U.S. Department of Health and Human Services, 2018a). Their challenges become compounded by unintended pregnancy.

Typically, to reduce the risk of transmitting HIV to an unborn child, prevention strategies occur during medical appointments. At this point, providers have the opportunity to educate patients on contraception use and preparing for a healthy pregnancy. Current guidelines recommend people living with HIV be clinically evaluated approximately every 6 months to control the virus and other potential infections (Centers for Disease Control and Prevention, 2019). However, pregnancy can occur at any time, including during the gap between laboratory tests and visits to a physician. Hence, women living with HIV may experience a pregnancy during the absence of care or when contraception is not available via a practitioner. Nevertheless, the timing of pregnancy is critical as it relates to controlling the HIV viral load to avoid transmission to an infant, ensuring the type of antiretroviral medication the woman is taking is safe during pregnancy and using contraception to avoid infecting a negative partner; all pose special dilemmas for women who are not planning a pregnancy (Centers for Disease Control and Prevention, 2019).

African American women have the highest rate of new infections, as well as account for the highest proportion of women living with the HIV (Centers for Disease Control and Prevention, 2017a). Additionally, the proportion of African American women experiencing unintended pregnancy was more than double that of non-Hispanic and white women (33 per 1,000) and choosing to terminate a pregnancy was higher among African American women than all other racial and ethnic groups (Kost, 2015). Thus, understanding unintended pregnancy among HIV-positive African American woman is important for successful efforts in improving maternal health, pregnancy outcomes and infant and child health, as well as reducing the risk of mother-to-child transmission of HIV and transmission to sexual partners if the woman does not know her status, opts out of HIV testing, does not receive treatment or does not discuss reproductive planning during routine care.

#### The Meaning of Unintended Pregnancy

Qualitative and quantitative researchers share the concern about imposing the researcher's philosophical paradigm and making assumptions when making observations. Surprisingly HIV research literature has not addressed the issue of the meaning of unintended pregnancy from the perspective of women with the exception of studies conducted in Sub-Saharan Africa. A study of Nigerian and Zambian seropositive women found knowledge about ARV therapy HAART was related less to childbearing desires whereas knowledge about prevention of mother-to-child transmission and use of contraception was associated with the increased desire for children (Bankole, 2014). Interviews were held with newly diagnosed HIV-positive women from South Africa who were visiting a clinic for their first CD4 T-cell count screening. Of the 106 women that

participated, 19.8% stated that they intended to conceive immediately, nearly two-thirds of the women stated that their partners were informed of their status, and all had engaged in unprotected sex three months before starting care (Mantell, Exner, Cooper, Bai, Leu, Hoffman, Myer, Moodley, Kelvin, & Constant, 2014). For women living with HIV, preconception counseling can decrease the risk of transmission to both partner and fetus (Savasi, Mandia, Laoreti, & Cetin, 2013) as well as provide a forum to address what behaviors and or health factors may exist that can lead to health risks during pregnancy (Aaron E, 2005; Minkoff, Marshall, & Liaschenko, 2014). There are limited studies that specifically explore the meaning and experience of unintended pregnancy among HIV-positive racial minority women from diverse socioeconomic backgrounds. This study addresses this gap in the literature.

#### Statement of Purpose

The purpose of this study is to explore the phenomenon of unintended pregnancy and using grounded theory to develop a model to explore unintended pregnancy among a sample of urban African American women living with HIV. Specifically, using a qualitative approach, this study explores urban African American women's experiences of unintended pregnancy; their beliefs, attitudes and norms surrounding sexual behavior, contraception, and reproduction; and experiences based on their HIV status in relationship to unintended pregnancy.

#### Research Questions

The following questions guide this exploration of unintended pregnancy among African American women living with HIV.

Research questions:

1. What common attitudes on unintended pregnancy are held among seropositive African American women?
2. What beliefs are shared among HIV-seropositive African American women who have experienced unintended pregnancies on seeking and utilizing health care?
3. What attitudes and cultural beliefs are shared among HIV-seropositive African American women regarding pregnancy? What psychological, social, cultural, and environmental factors function to avert or support healthy pregnancy decision making among HIV-seropositive African American women?
4. How do the beliefs, attitudes, psychological, social and cultural factors shared by HIV-seropositive African American women predict and explain the phenomenon of unintended pregnancy?

#### Rationale and Significance

Mother-to-child transmission of HIV has decreased with the advancement of prophylactic perinatal antiretroviral therapy and other available treatments (U.S. Department of Health and Human Services, 2018b) Nevertheless, pregnant women living with HIV are at greater risk for adverse maternal and newborn outcomes including preterm delivery, lower birth rates, premature rupture of membranes, urinary tract infections and delivery and postpartum complications (Arab, Spence, Czuzoj-Shulman, & Abenhaim, 2017). Moreover, women living with HIV who experience an unintended pregnancy that leads to live births are associated with additional poor health outcomes including delayed

prenatal care, mothers' smoking during pregnancy, mothers' reluctance to breastfeed as well as poor mother-child relationships (Barber, Axinn, & Thornton, 1999; Brown & Eisenberg, 1995; Chandra, 1995; Cheng, Schwarz, Douglas, & Horon, 2009; David, 2006; Gipson, Koenig, & Hindin, 2008; Joyce, Kaestner, & Korenman, 2000; Levison, Weber, & Cohan, 2014; Logan, Holcombe, Manlove, & Ryan, 2007; Mayer, 1997; Orr, Miller, James, & Babones, 2000; Pamuk & Mosher, 1988; Taylor & Cabral, 2002).

Limited studies exist that describe the perspective of African American women living with HIV and their understanding of unintended pregnancy. Designing effective interventions to motivate women to plan a pregnancy and reduce unintended pregnancies among women living with HIV requires an exploration of their beliefs, attitudes and social contextual factors associated with unplanned pregnancies characteristic of this population. However, such information is lacking. This research seeks to address this gap in the literature.

Unintended pregnancy is defined as a pregnancy that is mistimed, unplanned and/or unwanted (Mosher, Jones, & Abma, 2012). The U.S. has the highest rate of unintended pregnancies in the world. Of 4 million births per year approximately 1.5 million are unintended (38%) (Sonfield, Hasstedt, & Gold, 2014). Not all unintended pregnancies lead to a live birth. Unintended pregnancies among unmarried women aged 20–24 resulted in 34% of all abortions nationwide; ages 25–29 accounted for 27% (Kost, 2015). Deciding to abort occurs more often among unintended pregnancies (43% of pregnancies end in abortions) than the general population (Jatlaoui et al., 2016). From 2013-2016 in the U.S. there were over 1.5 million abortions among women aged 15-44 (Jatlaoui et al., 2016). Abortion is not a procedure reimbursed by Medicaid, except in

cases of rape, incest, or when a pregnant woman's life is endangered. For lower income women who experience unintended pregnancies Medicaid is the main insurer covering the cost of their unintended births (68% of the 1.5 million births per year in 2010). Half of the states in the country reported that 50 percent or more of births were financed by Medicaid (The Henry J. Kaiser Family Foundation, 2016). Over two million births are funded through Medicaid in the U.S. each year, with an estimated one million considered to be unintended (Sonfield et al., 2014). Tax payer and federal dollars dedicated to cost associated with unintended pregnancies nationwide were estimated to be over \$20 billion in 2010, of which \$14.6 billion in federal costs and \$6.4 billion in state costs were allocated (Sonfield & Kost, 2015). In 19 states, public cost related to unintended pregnancies exceeded \$400 million (Sonfield & Kost, 2015).

The incidence of unintended pregnancy is highest among women who are in poverty, unmarried, cohabiting with a partner, ages 20–24 and an ethnic or cultural minority (Centers for Disease Control and Prevention, 2015; Finer & Zolna, 2016). The rate of unintended pregnancy among impoverished women was five times more than the rate among women at the highest income level (Finer & Zolna, 2016). Additionally, women who did not complete high school (73 per 1,000 women) were the highest population to experience an unintended pregnancy of all educational levels (Kost, 2015). Percentages of unintended pregnancies decline as the level of education and age increased among women (Centers for Disease Control and Prevention, 2015). In a recent national health survey targeting heterosexual women at risk for HIV, 92% of HIV-negative women reported engaging in condomless vaginal sex in the previous year and

25% reported having condomless anal sex (Centers for Disease Control and Prevention, 2017a).

Women living with HIV who experience an unintended pregnancy face unique challenges including the effects of in utero exposure to HIV, the cost of medical care, as well as potentially stressful relations with the father and/or other family members. Heterosexual sex is the primary mode of transmission of HIV among women (86% of new cases) as compared to (13%) of the new diagnoses attributed to injection drug use (Centers for Disease Control and Prevention, 2017b) . In 2015, African American women were more than four times likely to be diagnosed with HIV attributed to heterosexual sex as compared to other races/ethnicities (Centers for Disease Control and Prevention, 2017b). Currently there are more than 280,000 women living with HIV in the US. Studies show women living with HIV continue to engage in condomless sex after their diagnosis (Du et al., 2015). Fifty percent of pregnancies among women diagnosed with HIV are unintended (Rahangdale et al., 2014).

#### The Researcher

My interest in HIV prevention and treatment is influenced by my professional and personal experiences. During my master's degree studies at the University of Pennsylvania I served as a research assistant on a federally funded community-based HIV prevention intervention that enrolled African American women and their adolescent children. From this experience my interest was sparked by challenges women faced in learning ways to promote the health of their children and themselves. After I received my master's degree, I became a project coordinator of the study. I worked collaboratively with the principal investigator to design, implement, and analyze both quantitative and

qualitative studies. From these experiences I developed an interest in the influence that economic inequities, culture, and social environmental factors have on the health of lower income urban women African American women.

It is not uncommon for researchers involved in HIV research to have a personal interest in HIV. By the time I completed my master's degree, I lost a very close family member and a friend to HIV and had an uncle who was living with AIDS. All three played instrumental roles and served as the impetus for my interest in women's health and HIV research. Earlier on when I decided to study unintended pregnancy among African American woman living with HIV, I recognized that my personal values and beliefs could influence my investigation. Eliminating the researcher's philosophical paradigm and assumptions from the research enterprise is not entirely possible (Everitt, Howell, & Stangl, 2008). I realized that my assumptions and values could shape and constrain my observations. Grounded theory allowed me to look beyond existing understandings on unintended pregnancies among women living with HIV.

Understanding respondent's meaning is an essential step for grounded theory analytical strategies.

Positionality refers to the placing of the researcher in relation to the social and political context of the study (Coghlan & Brydon-Miller, 2014). The stance taken by the researcher affects every aspect of the research process, from the conceptualization of the research questions or the problem, or the chosen design, to recruitment and outcomes (Coghlan & Brydon-Miller, 2014). The presence of power and powerlessness was recognized throughout data collection. I share the same race and gender as the research participants. I also shared with the participants a history of pregnancy having had two

children during my doctoral studies which placed me in the position as an insider. Still, my training and role as a researcher placed me in the position as a non-member or outsider (Glaser, 1978). My education background and socioeconomic status were different from the respondents. During reflection, I was aware of my outsider privileged status and how my values and life experiences differed. Thus, I focused on building a collaborative connection with the women by sharing that I am a mother, my experience and interest in woman's health and answering any questions they had about where I was from and why I chose this topic. I was cognizant of how I may be seen in an authoritative role and viewed as judging their values and behaviors around their HIV status, pregnancy intentions and their knowledge of HIV and pregnancy. I was very open with the women that I was not looking for any right or wrong answer but was interested in their views of the subject matter, and my desire to understand their experience about living with HIV and pregnancy.

### Assumptions

The maternal role attainment process is used as a conceptual tool directing this scientific investigation. The maternal role attainment process explores the process a woman experiences from the stage of pregnancy to delivering an infant, defined as a behavioral process, that leads a woman into her identifying herself as a mother (Mercer & Ferketich, 1995). During the commitment, attachment and preparation (also known as the anticipatory) stages, a woman adjusts psychologically and socially to pregnancy while continually evaluating her expectations of the maternal role. During this phase a woman begins to seek information and visualize herself as a mother or not (Mercer, 1981). Maternal role attainment is used to explore concepts related to maternal identity, self-

esteem, childbearing attitudes, health status, role strain conflict, family functioning, father or intimate partner relationship and social support. The maternal role attainment theory and the ecological framework strengthens this study in 2 ways: (1) forming a conceptual map of key personal and social environmental variables to explore; and (2) providing a contextual framework that compliments the subjective interpretative perspective directing this investigation and the use of qualitative research methods to understand aspects of unintended pregnancy as a phenomenon.

Four assumptions framed this study. The first assumption was, given the sensitive nature of the topic, the women may not answer all the questions in an honest manner (DeWalt & DeWalt, 2010). Second, the participants may experience the phenomenon of the living with HIV and unintended pregnancies differently (Dennis, 2014). Third, respondents had a genuine interest and desire to participate in the study (Head, 2009). The last assumption puts emphasis on collecting information directly from people who have knowledge of the phenomenon of study. Grounded theory involves the researcher gaining knowledge about the meaning of a phenomenon and how the meaning is influenced by the environment (Glaser, 1998). Lastly, women would be aware of the experiences of both living with HIV and have thoughts, opinions and experiences of unintended pregnancy.

### Conclusion

The health risks associated with HIV and unintended pregnancies are among the priorities of Healthy People 2020 (U.S. Department of Health and Human Services, 2010). One of the goals of Health People 2020 is to improve pregnancy planning, spacing, and preventing unintended pregnancy. Another goal is to prevent HIV infection

and its related illness and death (U.S. Department of Health and Human Services, 2010). Few studies have focused on the intent of pregnancy and the outcome of pregnancy systematically before or when a woman presents with the desire to reproduce. With the advancement of medication like Pre-Exposure Prophylaxis (PrEP) individuals can engage in unprotected sex to have a child, not having to rely on expensive and limited available reproductive technologies through infertility clinics (World Health Organization, 2017). However, even with these achievements, HIV medical care providers do not consistently integrate preconception care or family planning models into their treatment plans (Gavin, Pazol, & Ahrens, 2017). As a result, the health care needs of a HIV-positive woman who is of reproductive age may be addressed secondarily, generally, after a pregnancy has occurred and independently of intention. Providers and women must ensure that the HIV interventions that women receive compliment their sexual behaviors and needs ongoingly (Adimora, 2016). Interpersonal and social factors may influence high-risk behavior by individuals and lead to HIV risk as well as risk for an unintended pregnancy (Justman et al., 2015). Understanding the meaning of unintended pregnancy among African American HIV-positive women is imperative to designing programs to intervene and meet the populations' needs as well as overarching public health goals.

## CHAPTER 2: LITERATURE REVIEW

### Introduction

This chapter provides an overview of the relevant HIV literature. The discussion is divided into five sections beginning with a review of the literature on HIV and women. In section two attention is directed specifically to relevant epidemiological information on HIV among African American women. The third section reviews relevant literature on pregnancy and HIV and mother-to-child transmission of HIV. Section four explores current understanding on unintended pregnancy and its effect on women, their infants, families, and communities. Section five explores the literature on HIV stigma and cultural beliefs on pregnancy and women living with HIV held by the African American community.

#### *General Search for Literature Review*

In reviewing the literature from 2014-2019, exploring the topic of African American women, HIV and pregnancy, yielded over 5,000 peer reviewed articles. Limiting the search to unintended pregnancy resulted in 1,000 articles. There are a limited number of articles that exist that focus on the meaning of unintended pregnancy among African American women living with HIV. One study explored HIV-infected African American women's reproductive health decision-making, which also included the feedback of not only the women, but other stakeholders identified by the women, while another focused on the framework to collect data from the target population (Mutepa, 2016). Several peer reviewed articles focused on pregnancy related to men who have sex with men and women, contraception, adolescents and international studies (Brittain et al., 2018; Jones et al., 2017; Kottke et al., 2015; Murphy et al., 2017). Of the

articles reviewed, no empirical paper was identified that solely focused on what unintended pregnancy means among African American women living with HIV, despite public health goals to reduce mother-to-child transmission and unintended pregnancies. The lack of specific studies and the inability to concretely identify the needs of the population highlights the importance of this current research.

### HIV Transmission and Women

Antiretroviral therapy has become more effective and less complex since the first AIDS case was reported in the US in 1981. Research indicates that there are no differences in the response to antiretroviral medication for the treatment of HIV-1 based on gender, race or ethnicity (Currier et al., 2000). However, there are gender differences in the progression of HIV to AIDS, and immunity to HIV-1 infection. Contributing to gender differences is the increase in proteins released by a host cell in response to an HIV virus-infected cell in women compared to men (Addo & Altfeld, 2014).

Latex condoms are considered the most effective strategy for reducing the transmission of HIV as well as other sexual transmitted infections. Condoms also serve as an effective way to reduce pregnancy. More recently attention has shifted to biomedical prevention strategies to reduce acquisition by focusing on seronegative people taking a pre-exposure prophylaxis or PrEP. Although PrEP has proven to be an effective prevention strategy it does not protect against pregnancy or other sexually transmitted infections. Antiretroviral drugs (ARVs) are also prescribed as post-exposure prophylaxis to prevent mother-to-child transmission of HIV, and to reduce the risk of HIV infection soon after HIV risk sexual behavior (Centers for Disease Control and Prevention, 2018b).

One of the major factors influencing the spread of HIV is poor adherence to ARV treatment regimens, and misuse or lack of use of condoms and PrEP. Condomless HIV sexual risk behavior, and poor adherence to PrEP regimens are commonly associated with high rates of transmission among heterosexual men and women (Choopanya et al., 2013; Lasry, Sansom, Hicks, & Uzunangelov, 2011; Supervie, Viard, Costagliola, & Breban, 2014). In 2016, 24% of new HIV cases occurred through heterosexual contact (U.S. Department of Health and Human Services, 2019). One in every five cases of HIV are among women (Centers for Disease Control and Prevention, 2018a) . Women comprised 19% of the new cases transmitted through heterosexual contact (87% of cases) and injection drug use (12% of cases) (Centers for Disease Control and Prevention, 2018a). Significant progress has been made in studying HIV transmission among women. Advancements have occurred in part due to more sophisticated instruments and molecular microbiology laboratory technology. Notwithstanding these advancements further attention is needed to reduce the HIV disparities among African American women living with HIV who are of child bearing age.

#### African American Women and HIV

African Americans account for the highest proportion of new HIV diagnoses and HIV deaths compared to women of other races and ethnicities (Centers for Disease Control and Prevention, 2018a). The highest route of HIV transmission among African American women is heterosexual contact (Centers for Disease Control and Prevention, 2017b). African American women have the highest rates of new infection among women (Centers for Disease Control and Prevention, 2017a). Moreover, African American women have a higher probability of having male sexual partners diagnosed with HIV

(Centers for Disease Control and Prevention, 2018a; Homma, Wang, Saewyc, & Kishor, 2012).

### Unintended Pregnancy

Unintended pregnancy is defined as a pregnancy that is mistimed, unintended, or unwanted (Mosher et al., 2012). The United States has the highest rate of unintended pregnancies in the world. Of 4 million births per year approximately 1.5 million are unintended (38%) (Sonfield et al., 2014). Unintended pregnancies among unmarried women aged 20–24 resulted in 34% of all abortions nationwide; ages 25–29 accounted for 27% (Kost, 2015). Deciding to abort occurs more often among unintended pregnancies (43% of pregnancies end in abortions). From 2013-2016 there were over 1.5 million abortions among women aged 15-44 in the U.S. (Jatlaoui et al., 2016). Abortion is not a covered procedure reimbursed by Medicaid, except under cases of rape, incest, or when a pregnant woman's life is endangered. Medicaid does cover all family planning services related to pregnancy and the post-partum care. More than two million births are funded through Medicaid in the U.S. each year, with an estimated one million considered to be unintended (Sonfield et al., 2014). Public cost related to unintended pregnancies exceeded \$400 million in 19 states (Sonfield & Kost, 2015).

The incidence of unintended pregnancy is highest among women who are in poverty, unmarried, cohabiting with a partner, ages 20–24 and an ethnic or racial minority (Centers for Disease Control and Prevention, 2015; Finer & Zolna, 2016). The rate of unintended pregnancy among impoverished women was five times more than the rate among women at the highest income level (Finer & Zolna, 2016). Additionally, women who did not complete high school (73 per 1,000 women) were more likely to

experience an unintended pregnancy (Kost, 2015). As level of education increased percentages of unintended pregnancies decreased (Centers for Disease Control and Prevention, 2015).

#### African American Women and Unintended Pregnancy

African American women have the highest rate of unintended pregnancy of any racial and ethnic group in the United States (Kost, 2015). The proportion of African American women experiencing unintended pregnancy was more than double that of Hispanic and white women (33 per 1,000). (Kost, 2015). African American women are less likely to have access to adequate care, less likely to seek prenatal care, and are more likely to experience infant mortality, and have lower rates of prenatal care (March of Dimes, 2016; Mosher et al., 2012).

#### Unintended Pregnancy and HIV

Reports show women living with HIV continue to engage in condomless sex after their diagnosis (Du et al., 2015), which may result in an unintended pregnancy. Fifty percent of pregnancies among women diagnosed with HIV are unintended (Rahangdale et al., 2014). Unintended pregnancies have adverse health and economic consequences that are further complicated by having HIV. In a recent national health survey targeting heterosexual women at risk for HIV, 92% of seronegative women reported engaging in condomless vaginal sex in the previous year and 25% reported having condomless anal sex (Centers for Disease Control and Prevention, 2017a).

Unintended pregnancies that go to term may complicate a woman's HIV care and may also result in perinatal transmission (Rahangdale et al., 2014). Studies of HIV-positive women and unintended pregnancy conducted internationally, examined sexual

risk, barriers to contraception use, abortion, understanding of pediatric HIV, stigma, provider and patient communication as factors contributing to unintended pregnancy among women (Aaron & Levine, 2005; Andany & Loutfy, 2013; Bankole et al., 2014; Berhan & Berhan, 2013; Burgess & Purssell, 2017; Finocchiaro-Kessler et al., 2010; Mantell, Exner, Cooper, Bai, Leu, Hoffman, Myer, Moodley, Kelvin, Constant, et al., 2014; Martinez et al., 2012).

### HIV and Pregnancy

Sexual reproductive health and successful HIV continuum of care outcomes are intertwined for women living with HIV (McCall & Vicol, 2011). Addressing the problem of mother-to-child transmission of HIV is a global public health concern (Blake, Kiely, Gard, El-Mohandes, El-Khorazaty, et al., 2007; Gruskin et al., 2008; Hussey et al., 2014; Lampe et al., 2011; Squires et al., 2011). More than 8,000 women living with HIV give birth yearly (Centers for Disease Control and Prevention, 2016a). Additionally, an estimated 25% of HIV-infected women express a desire to become pregnant after an HIV diagnosis (Craft et al., 2007). Family planning services for women living with HIV remain limited. Poverty, access to health care, and housing are some of the major barriers to HIV treatment and care for women living with HIV (Centers for Disease Control and Prevention, 2016b; U.S. Department of Health and Human Services, 2014). Hypertension and tobacco use are also associated with poor pregnancy outcomes among HIV-positive pregnant women (Kreitchmann et al., 2014). Furthermore, antiretroviral treatment, with a low CD4+ count can lead to severe gynecological infections including an increased risk of the human papillomavirus (Aberg et al., 2014b). Few studies have systematically examined pregnancy decision making among woman infected with HIV.

Reports reveal HIV health care providers scarcely integrate discussions surrounding pregnancy into their treatment plans for women (Gavin, Pazol, & Ahrens, 2017), despite recent changes where these discussions come highly recommended to providers (U.S. Department of Health and Human Services, 2018b) .

In a sample of 889 HIV-infected mothers and their infants, 42% of HIV-infected infants mother tested positive for chlamydia trachomatis, neisseria gonorrhoeae, treponema pallidum, and/or cytomegalovirus (Adachi et al., 2018). Women in the study who tested positive for these infections had double the likelihood of transmitting HIV to their infants (Adachi et al., 2018). Current studies on pregnancy among women living with HIV focus largely on preventing vertical transmission of HIV to the unborn child (Arab et al., 2017).

#### Perinatal Transmission of HIV

Mother-to-child transmission of the HIV has decreased with the advancement of prophylactic perinatal antiretroviral therapy. Heterosexual women constitute the highest risk category for maternal infection of HIV (Forbes et al., 2012). Using proper prevention and treatment strategies, there is more risk involved in partner transmission than transmission from mother to newborn. In 2008 only 131 perinatal transmission cases occurred (1.5%) (Centers for Disease Control and Prevention, 2014). There is a 0.4% chance of mother to child transmission if a women begins maternal antiretroviral regimens at least one month before delivery (Forbes et al., 2012). Risk factors that lead to HIV infection in newborns are lack of prenatal care and breastfeeding (Rongkavilit & Asmar, 2011).

## Global Perspectives

The U.S. and Canada both recommend caesarian birth, avoiding breastfeeding and treating both mother and child with antiretroviral therapies to decrease and at times eradicate HIV infections entirely (U.S. Department of Health and Human Services, 2018b)(Office of AIDS Research Advisory Council, 2014). The British Association of HIV Guidelines recommends vaginal births depending on the viral load of the patient (2018). Since the onset of the AIDS epidemic, prevention of HIV-transmission to children has been an overriding goal. Today ARV therapy is proven to be both safe and effective for seropositive pregnant women (U.S. Department of Health and Human Services, 2018b). Combined antiretroviral therapy is preferred to treat HIV-infected pregnant women (U.S. Department of Health and Human Services, 2018b). Two types of antiretroviral medicines, ritonavir-boosted lopinavir- and atazanavir-based treatment, are favorable in pregnancy, while ritonavir-boosted darunavir- and saquinavir-based therapies are chosen as substitutes (Rough et al., 2018). As with seropositive patients in general, matching an antiretroviral therapy regimen to a seropositive patient during pregnancy is met with trials to determine the correct antiretroviral treatment (Rough et al., 2018; U.S. Department of Health and Human Services, 2018b). A study of Kenya and Uganda HIV serodiscordant couples who desired to have children found ART was willingly used including during preconception periods to prevent mother-to-child and partner transmission (Heffron et al., 2018).

HIV treatment and care services in Western countries for seropositive women commonly include education on mother-to-child transition of HIV in addition to content on social and cultural concerns. Women with HIV can transmit HIV to their infant

through breastfeeding. Yet, breastfeeding continues to be commonly practiced in many low-income countries. Cultural beliefs and economic needs often dictate breastfeeding. An infant feeding counseling intervention for seropositive mothers showed promising effects among breastfed children. The findings revealed that there was no difference in mortality risks between never breastfed children and breastfed children (Cournil et al., 2013). Seropositive women in the US are counseled to not breastfeed. Enrolling seropositive mothers in programs to promote the nutritional needs of the mother and fetus is standard practice. Despite the success in reducing perinatal transmission consideration is required in the health management of children born to women with HIV infection. For example, cultural practices often dictate that as a baby transitions from liquid to solid food mothers may chew food before giving it to an infant.(Maritz, Kidd, & Cotton, 2011). This practice could potentially result in a seropositive mother exposing her infant to HIV; there are reports that indicate children can become infected with HIV by eating food that was chewed by a person with HIV (Centers for Disease Control and Prevention, 2019).

Unintended pregnancy may not have the same meaning or implications for the woman who is not seropositive or African American. However, HIV research literature has not explicitly addressed the special circumstances that solely focuses on exploring unintended pregnancy among African American women who are living with HIV and exploring, planning or at risk for pregnancy. Researchers have not explored the African American women's experience from the standpoint of cultural-based conceptions of unintended pregnancy. To safeguard against HIV/STI transmission, lack of prenatal care, complications with HAART and to address both cultural and health concerns that can

lead to adverse pregnancy outcomes, targeted treatment is needed before seropositive women have a planned or unintended pregnancy.

#### Prevention Efforts

Although HIV treatment and care services for seropositive women have expanded, interventions focusing on pregnancy decision making are sparse (Centers for Disease Control and Prevention, 2013). Women living with HIV require more gynecological care than women who are seronegative. While the incidence rates of STIs are similar for seronegative and seropositive women, STIs in a woman living with HIV contributes to the shedding of HIV. Thus, STI infections may contribute to HIV progeny or an increase in viral activity resultant from the host cell being exhausted of all resources. Shedding of HIV can lead to an increased viral load found in bodily fluids, thus, increasing the ability of HIV transmission- both detrimental to a sexual partner and unborn fetus. Low CD4+ counts can lead women to severe infections, including an increased risk of high-risk types of the human papillomavirus infection (Aberg et al., 2014a).

There are more than 70,000 HIV-serodiscordant heterosexual couples in the U.S. that desire children, but may have limited access to safe contraception (Lampe et al., 2011). One study described how uninfected partners were relieved when they tested negative for HIV after several conception attempts (Ngure et al., 2014). The desire to have children may outweigh the risk of transmission to a partner or child (Ngure et al., 2014). A study by Finocchiaro-Kessler (2012) reported inconsistent condom use in a sample of seropositive women. This study also observed women being knowledgeable of

the risk of transmission, with none of the women informing their sexual partners of their decision to actively pursue pregnancy.

#### Philosophical Context: Epistemology

Applying grounded theory to guide this investigation requires a brief discussion of the philological and scientific foundations shaping this method of inquiry, specifically pragmatism and symbolic interactionism (Hewitt, 1991; Jones, Plowright, Bachman, & Poldma, 2016). Pragmatists assume all people align themselves with their environment to meet their needs (Hewitt, 1991). Drawing from Charles S. Peirce, William James, and John Dewey, pragmatism assumes that words and thoughts are tools for making predictions and developing interventions. This is a departure from other branches of epistemological research that view words and thoughts as mere descriptions of the phenomenon of interest (Jones et al., 2016; Morgan, 2014; Putnam, 2010). Symbolic interaction, which draws from pragmatism, offers a useful perspective for guiding this study by relying on the subjective meaning that people have based on their beliefs (Chamberlain-Salaun, Mills, & Usher, 2013; Mead, 2015; Mead & author, 2015). Based on pragmatic investigation and symbolic interactionism grounded theory, this study used this method to uncover the beliefs of African American seropositive women that shape the meaning they give to the experience of unintended pregnancies.

#### Contextual Boundaries

The maternal role attainment theory includes components of the Bronfenbrenner ecological system theory (Mercer, 1981), which allows a conceptual approach to understanding the diversity of interrelated influences on an individual. Figure 1 highlights the conceptual areas and ecological factors that potentially impact unintended

pregnancy and the desires to become a mother among seropositive African American women. According to Bronfenbrenner's theory, social environmental factors stratified as micro, mezzo, and macro levels influences based on the proximity to an individual (Bronfenbrenner & Ceci, 1998). These three levels help to identify and explore forces affecting the meaning seropositive African American women give to the experience of unintended pregnancy.

The microsystem concerns a woman's immediate surroundings, including social norms, interactions with family and activities that happen face-to face; it also consists of psychosocial variables experienced by individuals (Bronfenbrenner & Ceci, 1998). The microsystem encompasses the physical, psychological and cultural factors shaping her experience. The mesosystem comprises the interpersonal relationships between a woman and her immediate social relationship. This includes family, friends, fellow employees, church, and other social supports. The macrosystem consists of organizations and institutions, such as health and human services agencies, legal services and criminal justice organizations, health and social welfare policies, and local, state, and federal laws (Bronfenbrenner & Ceci, 1998). The concepts of the maternal role attainment theory served as a catalyst to explore meaningful concepts, categorization and comparisons in formulating questions for the data collection process.

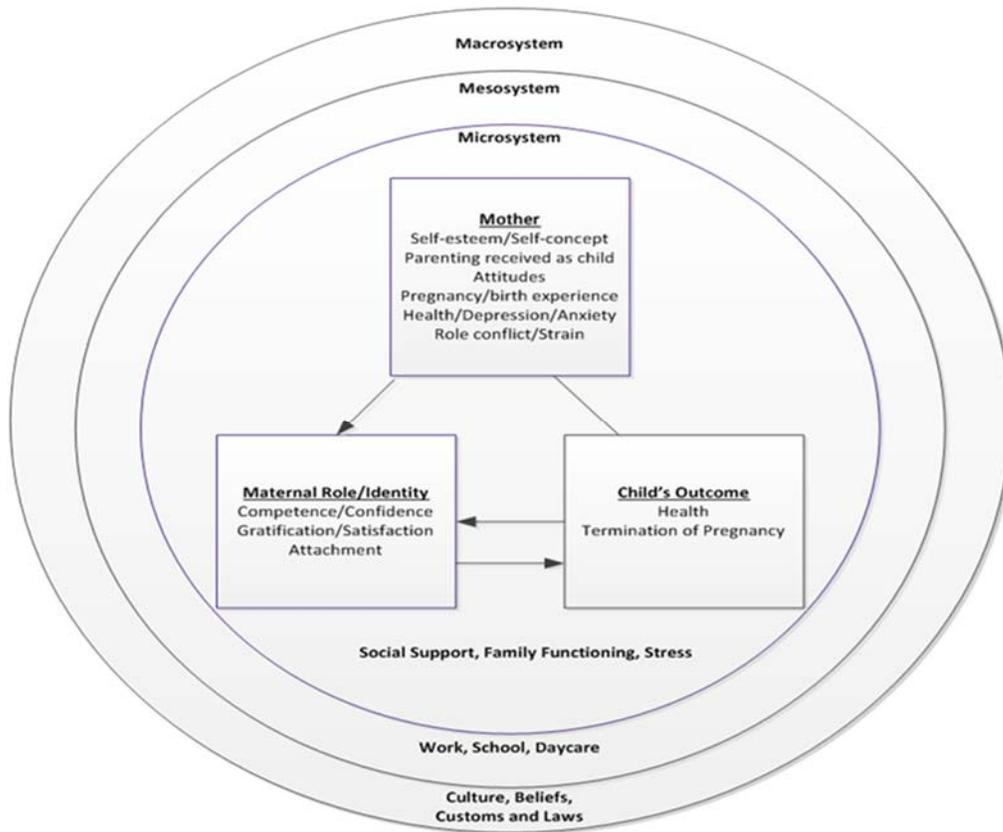


Figure 1: An illustration of the maternal attainment theory integrated into the micro system with influences from the meso and macro systems.

Figure 1 illustrates the proximity of the three levels of social systems with the relevant elements of interest identified within. The lines within the microsystem represent how the mother's experience may theoretically impact each level.

### Methodological Approach

The research questions guiding this investigation focused on the attitudes and beliefs of women living with HIV and their meaning of unintended pregnancy. Given the focus on women's perceptions and beliefs, the research methods employed in this study must draw from the narratives of women regarding their thoughts and experiences with unintended pregnancies. Qualitative research methods are used when there are limited data sources available about a particular area of interest, when variables pertaining to a phenomenon are unclear and unknown, and when established theories are not comprehensive for the area of exploration (Leedy, 2005). Thus, a qualitative approach utilizing in-depth interviewing is used. Qualitative research allows participants to provide insight into their experience.

A basic assumption of qualitative research is inductive reasoning whereby a researcher seeks to develop information from the data collected rather than be guided by preconceived findings. Thus, a woman's past and present experiences, along with their future expectations are used to generate knowledge. Qualitative research allows the researcher to access the experiences of the women to understanding of the subjective meanings they have regarding unintended pregnancies (Strauss, 2015).

Semi-structured interviews are highly compatible with the goals of qualitative research by allowing for the tailoring of questions to be appropriate and responsive to each woman's experiences. As such, semi-structured interviews are effective for

gathering data and for building rapport (Galletta, 2013). Semi-structured interviews allow the researcher to examine more carefully and to generate more comprehensive answers. Semi-structured interviews have the benefit of providing structure to strengthen internal validity, while allowing room for participants to provide additional information to better inform the research questions then by enhancing external validity as well (Harrell, 2009). The researcher can thus utilize open-ended questions and theoretically framed questions (Galletta, 2013).

This study employs semi-structured interviews to produce a multidimensional layer of data (Galletta, 2013). Funnel, quintamensional and tunnel methods were used to guide the interview. Funnel protocols utilize a wide range of questions then gradually move to specific questions (Harrell, 2009). Funnel protocols are used for questions that are deemed sensitive and private in nature, while the tunnel method includes a sequence of comparable questions that can be answered through rating; these questions are used for adherence and stigma questions. The quintamensional protocol is used to observe the intensity of a respondent's opinions and attitudes through assessing the degree of knowledge about an issue and the unbiased specific, rationale and intensity of attitudes expressed by the participant (Harrell, 2009).

### Grounded Theory

Grounded theory is used as an inductive methodological tool to guide data collection and analysis. Grounded theory historically has been used for developing theory that is rooted in data collected and analyzed by the researcher (Strauss, 2015). Grounded theory is inductively derived and meets four standards: fit, understanding, generality and control (Strauss, 2015). Fit requires that the theory relates to the anticipated data.

Understanding ensures the generated theory is reflective of those involved in the study. Generality warrants the theory is appropriate in diverse contexts. Control indicates the theory governs action toward the phenomenon. The goal of grounded theory is to produce a theory consisting of concepts that are generated directly from the participants. A theory developed in direct relationship to an identified problem can have greater meaning than a theory previously generated and applied to the problem (Glaser, 1998). As the researcher collects information about a phenomenon, theory is formed and advances during the analysis phases. Shown in Figure 2 is an overview of the Grounded Theory process from beginning to end.

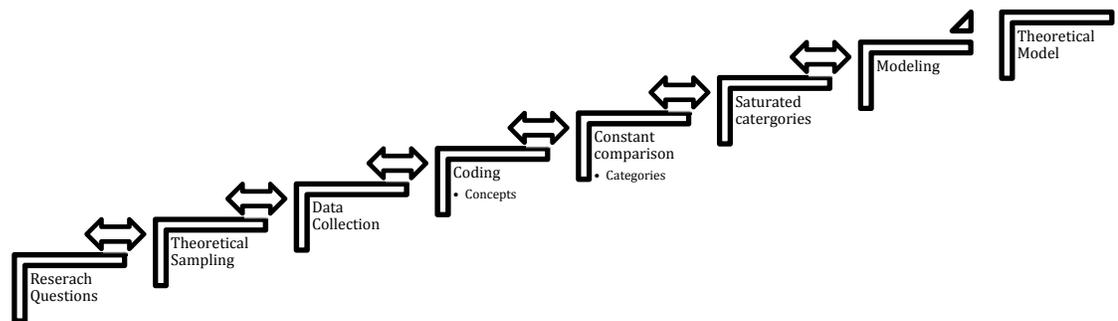


Figure 2: The steps to completing the grounded theory process are provided. Beginning with the narrative which is broad, through the steps the components are organized and contribute to the overall theory (Glaser, 1967).

### *Previous Use of Grounded Theory in HIV*

Grounded theory provides public health and social-behavioral researchers an organized and informed method of generating a theory from the subject matter expert that can provide insights for directing practice (Breckenridge & Jones, 2009). Grounded theory has been used in several studies to generate understanding of unintended pregnancy and motherhood. For example, grounded theory provided valuable insights on women who wish to achieve parenthood (Ellis, Wojnar, & Pettinato, 2015); women who are prescribed antidepressants during pregnancy (Nygaard, Rossen, & Buus, 2015); pregnancy and employment (Quinn, 2016); as well as childbearing and HIV (Saleem, Surkan, Kerrigan, & Kennedy, 2016; Walcott, Hatcher, Kwena, & Turan, 2013). Using grounded theory allows data collection to occur with an open mind and with an understanding that pre-existing theories may exist allowing the researcher to place emphasis on component(s) of the targeted phenomena, characteristics or distinct points made by the participant (Smith, Carter, Dunlop, Freeman, & Chapman, 2017). Although the use of pre-existing theories is viewed as antithetical by some proponents of epistemological research, specifically grounded theory, some argue that this approach is beneficial for constructing a problem and analyzing data (Thornberg, 2012).

### Conclusion

Whether a woman living with HIV receives care and adheres to their ARV treatment regimen the liability to become pregnant remains. Effective strategies exist for reducing the risk of seropositive women infecting their children and their sexual partners. Still, a deficiency remains in the literature on HIV prevention and treatment for

women regarding pregnancy decision-making (Blake, Kiely, Gard, El-Mohandes, & El-Khorazaty, 2007; Gruskin et al., 2008; Hussey, 2010; Lampe et al., 2011; Squires, 2011).

Needed are behavioral interventions that focus on pregnancy decision making among seropositive women of child bearing age. Moreover, needed are models that are culturally responsive that integrate preconception care with HIV care and treatment programs for seropositive women (Centers for Disease Control and Prevention, 2014).

## CHAPTER 3: RESEARCH AND METHODS

### Introduction and Overview

This chapter presents the research design; data collection, management, and analysis strategies. Few studies examine unintended pregnancies among seropositive women. Qualitative methods have been used to explore the phenomenon of unintended pregnancies among African American women. This study will use in-depth interviews to explore a) common attitudes held among women regarding unintended pregnancy; b) their shared personal and cultural beliefs about seeking health care and engaging in the continuum of HIV care; c) their beliefs regarding pregnancy; and d) psychological, social, and social environmental factors characterizing the experiences of seropositive and unintended pregnancy.

Glaser and Strauss' (1967) grounded theory process was utilized. Grounded theory allows the researcher to explore and build on information from different participants and compare how their similarities and differences can be used to build into explaining a phenomenon. Data gathered from interviews were analyzed for patterns and descriptors that lead to general concepts about the phenomenon under investigation. Concepts then become the foundation for propositions. Employing grounded theory thus allows for rich insights into the experiences of seropositive African American women and unintended pregnancy. Each participant was probed to provide their views on unintended pregnancy, attitudes and experience surrounding unintended pregnancy, views on contraception, stigma, living with HIV and social support.

## Research Design and Method

This section describes the research design, recruitment, data collection, and data analysis strategies used in this study. Limited studies are available that examine the unintended pregnancy among African American women living with HIV. Using a qualitative design, the topic of unintended pregnancy was explored in the natural environment among women seeking health services who can become pregnant. The dissertation explores this phenomenon through in-person interviews with the following research questions in focus: a) what are common attitudes on unplanned pregnancy held among African American women living with HIV; b) what are common beliefs held among African American women living with HIV who have unplanned pregnancies about seeking health care and engaging in the continuum of health care; c) what are common beliefs surrounding among African American HIV-positive women and pregnancy; and d) what are the psychological, social, and contextual factors that are characteristic of African American women living with HIV who experience an unplanned pregnancy. A qualitative approach of in-depth interviewing was used to most effectively respond to the research questions.

### Institutional Review Board (IRB) Approval

Temple University's Institutional Review Board (IRB) approval was granted prior to data collection in this study. The Temple IRB approval was shared with all recruitment and data collection sites. For Site 1, a health clinic in a children's hospital, the researcher completed the entity's IRB application and was granted an additional approval. For Site 2, a health clinic in a university hospital, the researcher completed the entity's IRB application and the reviewer determined this study was exempt. For Site 3, a community-

based organization with a health clinic, the researcher shared the university approval with the entity's IRB Coordinator, after reviewing the entity determined the study was exempt from IRB review.

### Research Sample

The sampling frame comprised seropositive African American women of child bearing age (21-49 years of age) and capable of becoming pregnant. Access to potential participants was granted through several HIV clinics in Philadelphia. Homogeneous sampling is a purposive sampling technique that focuses on potential participants that have common characteristics in terms of age, health status, experiences and careers (Etikan, 2016). To explore the phenomenon of unintended pregnancy homogenous sampling allowed for the selection of women with similarities related to study inclusion.

#### *Participants*

#### *Eligibility Inclusion/Exclusion*

The study sample consisted of women, age 21-49, English speaking, African American, HIV-positive, and capable of becoming pregnant, and did not have a reversible device or permanent method or procedure that prevents pregnancy like an IUD or implant, or had a procedure where the participant is considered sterile. Women were excluded from participation if they exhibited developmental delay, intellectual disability or communication challenges that would prohibit the researcher from completing an interview.

#### *Recruitment*

Sampling starts when the researcher brings their interest and desire to understand a phenomenon (Corbin & Strauss, 2008). Based on the researcher's experience,

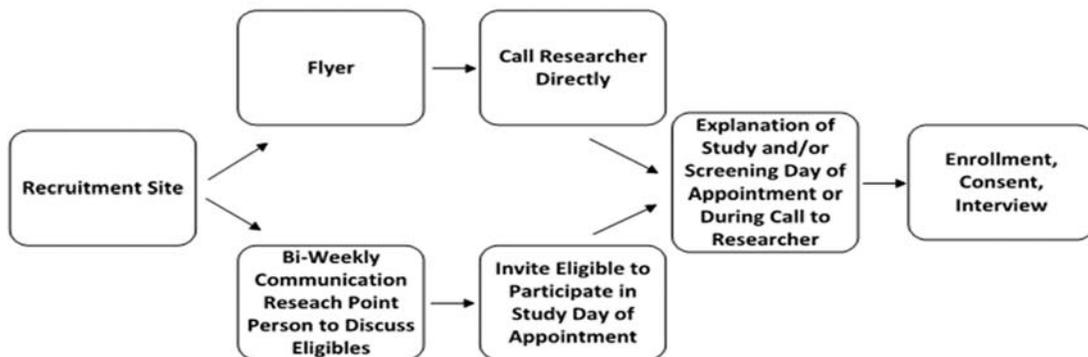
individuals, organizations, health entities, or community groups affiliated with the phenomenon of study can be selected (Corbin & Strauss, 2008). The potential participants were patients recruited from three HIV clinics and one community organization that has a HIV clinic in Philadelphia, participants were successfully recruited from three sites. Recruiting from community clinics offered greater access to eligible potential participants through their ability to identify and directly recruit potential research participants from a pool.

Since the beginning of the HIV epidemic all recruitment locations have provided primary care, consumer education and/or advocacy for those living with or affected by HIV/AIDS in Philadelphia. All are known to provide culturally competent comprehensive primary care, and state of the art HIV primary care to low income members of the community, along with research, consumer education, social services and outreach to people living with HIV and those who are at high risk, including family members, communities with high rates of HIV, formerly incarcerated persons, and young people at risk; and access to the most advanced clinical research in HIV treatment and prevention. The site, overview of services and recruitment point person(s) are provided (see Appendix A – Table 2 Recruitment Sites).

### *Participant Selection*

The researcher established relationships with the point person at each of the three clinics through an introductory meeting. Prior to recruitment activities, meetings were held with a staff representative to review Institutional Review Board requirements and receive feedback on questions to ensure the researcher was using terminology and questions that would be familiar to the participant. All the sites provided a staff contact

person to conduct initial screening and refer potential participant to the researcher. Flyers were used to solicit participants through self-referral at all sites. Additionally, two of the sites provided a panel of patients expected to attend appointments. This panel was used to identify potential participants and for patients that met the criteria for office staff to invite them to participate during routine appointment reminder calls. Potential participants were informed about the study and given the option to contact the researcher directly or be introduced to the researcher at the end of their medical appointment. See Appendix F for a copy of recruitment flyer. Biweekly meetings were held to discuss participant flow. An overview of the recruitment process is provided in Figure 3.



*Figure 3:* A process showing recruitment strategies from the site, collaboration with the site staff, eligibility to the time of enrollment.

All participants from the clinical sites were initially approached by a staff point person. The community-based site provided potential participants with the study flyer that contained a telephone for contacting the researcher. The appointed clinic contact provided the researcher with the first name and appointment time of participants who agreed to participate via the health facilities' secure email portal where emails are automatically deleted in a 30-day period. Emails were not forwarded, and no materials were printed. Appointment times were used for scheduling purposes for the researcher.

Upon arrival to the clinic sites, the research point person would place the researcher in a conference room and the participant was introduced to the researcher as "Patient". For Site 3 the participant called the researcher via the number provided on the recruitment flyer, the study was explained and a screening for eligibility was conducted, an appointment time and location was provided. The participant did call the day of the appointment to make sure she had the right location that was provided by the researcher via the point person at the clinic. The phone number the participant called from was not stored and was deleted immediately after the conclusion of both calls.

At the appointment, the potential participants were provided an overview of the study and screened again for eligibility. If still interested all were guided through the interview process beginning with informed consent provided verbally, an overview of the question and answer protocol, answering any questions they may have, and what to expect once the interview concludes.

### *Interview Guide*

The initial research question in grounded theory is open-ended and identify the phenomenon of interest without making too many assumptions about it (Strauss, 2015).

To guide the research design, knowledge gained from the literature review on risk of unintended pregnancy and HIV, the maternal attainment theory process and discussions with the dissertation committee were used. Questions for this study were formulated and tested with members of the dissertation committee, sent to clinical staff at recruitment sites and testing among the first three participants for feedback. Corbin and Strauss (2008) suggest using the first three to four interviews as guides to center and focus through questions the conversation around the phenomena to reduce the number of interviews that follow (Corbin & Strauss, 2008). In addition to open ended questions, demographic data was collected at the end of the interviews via a survey, see Appendix B for all questions.

The number of possible interviews for this study was contingent on the nature of the phenomena studied and the experience of the researcher. Finding women who do not have a reversible permanent sterilization birth control method and/or woman who were willing to discuss a sensitive topic like pregnancy contributes to this subpopulation being hard to reach. The skill set, knowledge base and comfort of the researcher can influence sample size (Morse, 2000). Researchers with developed skills in interviewing do not require as many participants as a new and less experienced researcher (Morse, 2000; Strauss, 2015). In conclusion, researchers cannot establish a sample size until they have begun data collection and ongoing analysis (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Thus, the number of interviews for this research was not firmly established; rather data collection concluded at the point of theoretical saturation.

Theoretical saturation is centered around the researcher during data collection reaching a point where there is no new information emerging from the data source, a

category is established and fully matured having properties with no instance of new information being introduced that could change the properties of the category, and associations between categories are well developed and authenticated (Corbin & Strauss, 2008). Like other qualitative techniques there is no required number of interviews recommended to reach theoretical saturation (Corbin & Strauss, 2008; Glaser & Strauss, 1967).

### *Constant Comparison and Theoretical Sampling*

Constant comparison and theoretical sampling are key components of grounded theory. Constant comparison is a technique used to examine if the data aligns and continues to align with indicators and then established conceptual codes that emerge during the coding of data (Glaser, 1978). Constant comparison shapes and validates the developed categories by establishing their characteristics and scopes (Holton, 2010). Constant comparison allows the researcher to collect data, code data and produce concepts and its dimensions until a category is saturated (Glaser, 1978; Holton, 2010). The constant comparative process occurs during open coding and selective coding. Constant comparison involves comparing incidents to establish precision, consistency and differences in concepts, then using additional data to compare to develop theoretical properties. Lastly, concepts are finally compared against each other to establish a relationship between concepts and indicators into a hypothesis to become the theory (Corbin & Strauss, 2008; Glaser & Holton, 2004). Constant comparison and theoretical sampling allow the researcher to purposefully decide what data to collect in order to support theory development (Holton, 2010).

In using grounded theory theoretical sampling occurs as the data collection progresses and is guided by the emerging theory (Draucker, Martsolf, Ross, & Rusk, 2007). Theoretical sampling occurs after the researcher collects data from a few participants based on the initial questions, then following the first data collection, immediately coding and analyzing the data with the purpose of deciding what forthcoming data could strengthen the developing theory (Glaser, 1978). The researcher then identifies more participants and completes the theoretical sampling process while confirming and/or exploring counter information to the findings (Glaser, 1978). Theoretical sampling is an ongoing process that allows the researcher to navigate between data collection and analysis until accomplishing theoretical saturation. Theoretical sampling for the development of a theory is directly related to the recruitment and obtainment of information from new participants, prior data collection, observations made with participants, and the literature review (Draucker et al., 2007).

#### Data Collection Methods

Interviews were conducted in a private room at each of the sites. Participants completed an interview on average in 45 minutes. Interviews were digitally recorded and transcribed verbatim. A semi-structured format was used, allowing participants and the researcher the flexibility to expand upon the specific questions proposed on the interview protocol.

#### *Data Management*

Interview data was documented in two ways: (1) using a digital audio recorder and (2) written transcripts. Digital recordings of interviews establish a reliable record of the discussion with the participant, it allows the researcher to reflect on voice, tone and

capture laughter or other expressions of emotion while allowing the researcher to be fully present (Arksey, 1999). Audio recordings were transferred to an encrypted laptop in a password protected file immediately after the interview concluded and was labeled with an assigned number. Transcriptions were transcribed verbatim using a third-party protected through a non-disclosure agreement. All files were listened to and read by the researcher to ensure accuracy.

Handwritten field notes were also taken during interviews. Field notes were collected as a means of documenting needed contextual information. Field notes were taken containing nonverbal communication (crying, affect, knees shaking, etc.); and questions requiring additional probing. Handwritten field notes taken during each interview were labeled with the participant's assigned number and scanned into a password protected separate file on an encrypted computer. They were used in addition to transcripts for analysis. (See Appendix C for a sample of field notes).

### Data Analysis

Data collection and analysis in grounded theory occur simultaneously until theoretical sampling is concluded (Glaser & Strauss, 1967). Data analysis has three processes of coding that leads to concept development. The data analysis process includes open, axial and selective coding (Corbin & Strauss, 2008). Saldaña (2009) defines a code as, “a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data” (p. 3). These codes contribute to establishing themes, categories, subcategories and relationships between both and lastly the generating of concepts and their dimensions that lead to the development of a theory. Coding of data from interviews generates initial

codes and begins the memo writing process where codes are corrected using new information, deleted, modified or adjusted to fit the data discovered (Glaser, 1978). Coding generates concepts, which pertain to how a phenomenon can be grouped to form categories. Memo-writing allows the researcher to conceptualize the dimensions and properties of codes, categories and work towards an emerging theory (Glaser, 1978). During open coding the researcher uses constant comparisons which are constantly modified until saturation occurs, (Glaser & Strauss 1967).

### *Open Coding*

Open coding is the first process in data analysis that leads to theory development (Glaser, 1978). It involves taking unabridged raw data, reviewing line by line and separating the information into small doses to analyze into as many categories that could fit (Glaser, 1978). The goal of open coding is to provide the researcher free range to identify and report what is shared about the subject of investigation while removing the barrier of the researcher's preconceived notion and ideas about the phenomena that may exist (Glaser, 1978; Corbin & Strauss, 2008). During open coding information is singled out; it involves the incremental advancement of knowledge about the phenomena through recognizing similarities and differences into wide-ranging categories. Open coding happens early in the analysis process, so the researcher can identify, explore and describe the characteristics of the phenomena as early as possible and as they unfold and points the researcher in the course of theoretical sampling (Glaser, 1978).

During the open coding process, the identification of new terminology is introduced, a distinctive identity shared among the participants develops and the researcher begins to express and consolidate his or her ideas (Corbin & Strauss, 2008).

Common ideas about the phenomenon are advanced through the grouping of shared ways of discussing the phenomenon to form categories and subcategories (Corbin & Strauss, 2008). Once solidified the categories and their qualities become the foundation for theoretical sampling, resolving discrepancies between new information and established categories through constant comparison, and debunking preconceived notions (Corbin & Strauss, 2008). Table 1, in Appendix A, demonstrates the different coding phases.

### *Axial coding*

Axial coding consists of establishing relationships among the open codes. The categories that are established during open coding are reviewed in the context of the subcategories and their properties that are established by the researcher (Corbin & Strauss, 2008). The relationships of the two are then confirmed and elaborated upon using support from the data. Because of axial coding, the development of additional new categories or categories that are not as open or obvious may be established (Corbin & Strauss, 2008). The relationships that are established are assumed and injects a deductive approach until the researcher can verify consistently through data analysis that the hypothetical relationship exists with support of fresh data from theoretical sampling. In axial coding, the categories begin to reveal how the phenomenon of study reaches a level of consistency in which regularities, patterns and differences are given order (Corbin & Strauss, 2008). During this phase researchers become enlightened that some properties of the phenomenon are multifaced, complex and need further exploration through theoretical sampling.

### *Core Variables and Selective Coding*

As the researcher proceeds with constant comparison during data collection and analysis, the researcher begins to establish new ways of thinking about a phenomenon and engages in theoretical sensitivity (Glaser & Holton, 2004). Theoretical sensitivity requires the researcher to develop “theoretical insights and abstract conceptual ideas” from the data to “generate concepts from data and relate them according to normal models of theory in general” (Glaser, 1978, pp.1-17; 1992, pp.27-30, 49-60). Core variables are developed which explain the differences found throughout the data and emphasizes the problem that is the focus of the study (Glaser & Holton, 2004). The core variables are theoretically coded and then used to build the theory. The core variable builds the narrative, the story line and explains what occurs in the theory that is produced from the data collected. During selective coding core categories are provided descriptive details and selected for theory building (Strauss, 2015). The researcher defines two types of categories, “sociological constructs and in vivo codes” (Glaser, 1978, p. 70). Sociological constructs are built on the researcher’s knowledge of the field of study both from research and scholarship while in vivo codes places emphasis on the spoken words used by the participants (Glaser, 1978; Manning, 2017). Typologies of the variables are developed to understand the relationships between the different concepts and reduce the number of variables that do not earn their way into the theory (Glaser, 1978). The final core category represents the phenomenon of the study. Corbin and Strauss (2008) stated that this central or core category should have the explanatory power to “pull the other categories together to form an explanatory whole” and “should be able to account for considerable variation with categories” (p. 146). During this level of coding, theoretical

saturation is reached, and no new information emerges from the analysis (Strauss, 2015). During selective coding the meaning, conditions, intervening conditions that are associated with the core concepts are matured using as much data as possible. Once the meanings are saturated, diagramming occurs which assist the researcher in creating interrelationships between the categories (Corbin & Strauss, 2008). For a theory to have the power to explain a phenomenon, each of its categories and subcategories must have conceptual density.

#### *Theoretical Memos*

In addition to coding, producing theoretical memos is a pivotal component of doing grounded theory. Writing theoretical memos allows the researcher to challenge their thinking and record their conceptual thought process while coding and analyzing, which reinforces theoretical sensitivity (Holton, 2010). This process helps the researcher keep track of all the categories, dimensions, properties, propositions, and generate questions that develop from the coding process (Strauss, 2015). Memos vary in method and length, the type of coding the researcher is performing, and must continue until the very end of study (Corbin & Strauss, 2008).

#### *Computer Assisted Qualitative Data Analysis Software (CAQDAS)*

NVivo was used to analyze all data in this dissertation research. NVivo is a qualitative data analysis (QDA) computer software package founded by QSR International. It provides the researcher with the ability to upload text-based and/or multimedia information and conduct various levels of analysis of data as required. NVivo offers coding, sharing of data files across platforms, and allows for a wide range of qualitative research designs and data analysis methods such as grounded theory. The first

step in coding is to review the narrative. Using, NVivo, after transcribing, the researcher read and listened to all details of the transcripts and developed open codes. In NVivo, audio-files are uploaded with the transcripts thus the researcher could listen and read when creating sociological constructs and in vivo codes (nodes). Transcriptions were read line-by-line and relevant excerpts were manually coded to new and or existing nodes. From these nodes, the first level of tree nodes was created and coding to these nodes continued with the rest of the documents. Data collection occurred, and additional nodes were added in the process and nodes were also aggregated to produce a parent node. Information of the nodes were constantly reviewed, and assigned colors were added to create a visual of the coding process allowing the researcher to see high and low frequency codes and depth of the use of the code (supported by a word or a paragraph). When the analysis process reached a progressive stage, the researcher began to merge, reorder and refine nodes. The last stages included creating reports, queries, tables and developing visual illustrations of the data to develop the theory. In addition, theoretical memos were also created using Evernote which feeds into NVivo for documenting the thoughts, uncertainties, questions and insights that were emerging during the researcher's data analysis.

### Conclusion

To explore the phenomenon of unintended pregnancy among African American women living with HIV required the researcher to understand the meaning from the perspective of the participant. The qualitative research interview allowed the participant to share their story and experience, offering the researcher an in-depth analysis of the topic that cannot be solicited from a quantitative research design. The use of grounded

theory complements the exploration of this topic because it recognizes the need to use an inductive approach to scientific discovery (Remenyi, 2014). The methodology and method chosen was appropriate for this study providing an outline to address and explore the phenomenon respectfully and constructively.

## CHAPTER 4: FINDINGS

### Introduction

The purpose of this study was to generate information to advance current understanding of the phenomenon of unintended pregnancy experienced among urban seropositive African American. The study explored unintended pregnancy and the common beliefs of seropositive urban African American on unintended pregnancies. The first section of this chapter provides an overview of the participants and their characteristics. The second section presents themes that emerged during analysis supported by participant responses and interpretation of the findings. The third section provides an overview of the emergent theory.

### Participants

Purposive sampling was used to recruit participants from three clinics. A total of fifteen interviews were conducted. Specific criteria for participation included women, between the ages of 21-49, African American, living with HIV with no permanent method of birth control and currently not pregnant. Within the sample of fifteen interviews, interview transcripts and demographic data from twelve participants were analyzed; three participants were found to be ineligible due to disclosing they had an intrauterine device during the interview. During the constant comparison process, twenty-seven memos were generated capturing the conceptual and methodological development of the theory. These memos ranged in length from a few lines to mapping. The participants had an average age of 31 ranging from 21 to 47 years. All the women were African American. There was little variation with education, 8 of the participants achieved a high school diploma, 2 attended some college and 2 did not complete high

school. Seven of the participants reported as single, 2 married, 1 engaged, 1 in a monogamous relationship and 1 living with a partner. Five of the participants reporting an annual income of less than 10 thousand, five reported 10-20 thousand and two reported 20-30 thousand. The participants had an average of 2 children (range 0-9 children), two were grandparents and the average pregnancy while living with HIV was 1. The average age of diagnosis was eighteen years, living with HIV thirteen years and two of the participants were diagnosed at birth. After completing the consent process, an interview was arranged by the research point of contact at the clinic location. Appendix A, Table 3 provides an overview of all participant demographics. The following contains anecdotal information using pseudonyms for each participant.

*Marie, 30 years old, Site 1*

Marie is a wife and mother of three children, ages 15, 8 and 6. She is a Muslim woman who rents a home with her husband and children. Marie lived in foster care her entire childhood. Her mother was on drugs and her father was an alcoholic. She knows her mother who has nine children; she is the sixth child from her mother. She was diagnosed with HIV at the age of 17 through a relationship she had with a person that disclosed to her he was living with HIV a year after he tested positive. Marie had one child prior to her diagnosis and two pregnancies post her diagnosis. She has received care from Site 1 since her diagnosis. She planned none of her three pregnancies. Marie delivered her first pregnancy vaginally and her other two children post her HIV diagnosis through caesarean. She reports that she has a hard time staying adherent to her medication and that she has experienced lower quality health services because of her

diagnosis. She considers her husband, father and several of her siblings her support system. She has disclosed her HIV to close family and friends.

*Cheryl, 39 years old, Site 1*

Cheryl is a single woman who has four children, 2 boys and 2 girls who are 23, 21, 14 and 2 years of age. She holds a fulltime job as a certified nurse assistant. Cheryl found out she was HIV positive during the pregnancy of her oldest child. She was 16 years old. None of Cheryl's children are HIV positive, however, she gave all of them AZT because she missed several doses of medication during her pregnancies. Cheryl describes her mother as a great support for her wellbeing and seeking healthcare. She is the oldest of five children. Her mother was there when she received the results of her HIV test. She immediately was enrolled in a HIV teen program. Cheryl has had several partners since her diagnosis, she disclosed her diagnosis with at least two of her sexual partners. She contributes her not disclosing her status to stigma. In addition to HIV, Cheryl also has several other medical conditions, including diabetes.

*Shay, 33 years old, Site 1*

Shay is a single Christian woman who is diagnosed with schizophrenia, depression and a recovering addict. She has been sexually active since the age of 13 and was diagnosed with HIV at the age of 19. Shay has never been pregnant but did experience a pregnancy scare. It was at this appointment where Shay thought she was pregnant when she found out about her HIV status. She was accompanied by her mother, who has since died. Shay lives in the home with her father, has experienced several psychiatric hospitalizations and currently goes to an out-patient program daily. She is working on obtaining her GED and attends church regularly. She receives support for

her addiction and healthcare needs from her father, step-father and siblings. She is open about her status with her family.

*Sade, 31 years old, Site 3*

Sade is a Christian single woman who has an eleven-year-old daughter. Sade comes from a very large family; she has twelve sisters from her mother and 5 brothers from her father. She is the third oldest child. Sade found out she was HIV-positive when she was pregnant with her daughter. She thought at first her child's father transmitted the virus, however, was later approached by a person who apologized for infecting her. Sade took medication during the last eight months of her pregnancy, had a cesarean delivery and gave her daughter AZT after birth. Her daughter does not have HIV. Sade has dealt with domestic violence and stigma in several of her close relationships post her diagnosis. She believes people she disclosed her status to told others without her consent and teased her about being HIV positive. Sade wants to be a peer advocate for HIV education, however she is protective about her daughter and loved ones who she believes may be teased if other people find out about her status. She is open about her status to sexual partners. She has also had a sexually transmitted infection post her HIV diagnosis.

*Shana, 21 years old, Site 1*

Shana is a single young woman who lives with her parents. Shana was diagnosed with HIV when she was seventeen years old. She started dating and became sexually active with a young man in high school. The first time they used a condom, subsequent times they did not. After engaging in sexual intercourse for a short period of time the young man shared with Shana he was born with HIV. She continued to have unprotected sex with him. During her junior year in high school, Shana stayed overnight from her

parent's house for three days without permission. When she returned home, her mother insisted she go to the doctor to get a pregnancy test and test for sexually transmitted infections. It was at this visit Shana found out she was HIV positive. Since graduating from high school, she continues to have a relationship with the same partner from high school but admits having sexual intercourse with other people. She has not shared her status with her sexual partners and does not always use protection. Shana has had one pregnancy scare since high school. Her immediate family knows of her diagnosis and some family members. She states they treat her differently; her cousin gives her a designated spoon and bowl to use every time she visits. In high school, she experienced rumors of her being HIV positive because some people knew who her boyfriend was.

*Joy, 25 years age, Site 1*

Joy perinatally acquired HIV from her mother who is a recovering addict. She was not raised by her mother. Before she could remember, Joy was adopted by a woman who raised her until her recent death. She now resides with her adoptive father and sibling. Joy was informed about her status when she was eleven years old. Growing up, Joy always attended camps for children with or affected by HIV or AIDS and does not recall a time when she did not have to take medication. Her adoptive mother was also open with her about the details of her adoption, her status, the use of birth control and facilitated a relationship between Joy and her birth parents. Joy was told about her HIV status and what it means regarding her medication when she was eleven years old by her provider and adoptive mother. Joy does have a boyfriend that she hopes soon to start talking about having a family. Her boyfriend is taking PrEP and knows about her status.

She does not share her status with anyone outside her immediate adoptive family, her boyfriend and her natural parents who are both living with the virus.

*Lilly, 24 years old, Site 1*

Lilly was perinatally infected with HIV. She was born with spina bifida and must walk with crutches. She describes herself as having a sick childhood where her mother cared for her and she was hospitalized several times. Lilly has received care at Site 1 since she was born. Growing up she attended special needs summer camps as well as summer camps for kids and teens affected by HIV or AIDS. This is where she formed many of her friendships. Lilly's father was not involved in her life. She is her mother's only child. Lilly wants to be in a relationship and wants children one day, especially because she comes from a very small family. She has concerns with her ability to find a partner because of her physical limitations, but also with sharing her status. Despite these concerns, Lilly has had several sexual partners, some of whom she has not used protection and wonders if she infected them. She has shared her status with one boyfriend and a close friend. She has not experienced stigma personally but friends she acquired in high school make jokes about HIV and she knew a girl that was teased and left high school because of her status. For this reason, she does not share her status openly. Lilly is very close with her mother who is a peer educator for women staying adherent to antiretrovirals in the community in which they reside.

*Angel, 30 years old, Site 1*

Angel resides with her 1-year old son and her son's father. From her early adult years, Angel took care of her cousins' daughter that she states is her god-daughter, however recently the daughter was returned to her mother's care. Angel always wanted

her own child that no one can take away from her. She was in a long-term relationship and planned on having a child. Angel became pregnant with her daughter that would be seven-years old. She also found out she was HIV-positive during her prenatal visit with her daughter. Angel was 23 years old. Both Angel's partner and the daughter were HIV negative. Angel experienced death several times during the past four years. She lost her daughter's father, her own father, and her daughter consecutively. Angel is in a new relationship with her boyfriend and they recently had a child. Angel describes herself and her son as having undetectable viral loads. She did not disclose her status to her son's father; he found out when he looked up the medication the doctors gave her intravenously when she was in labor. Angel describes her support system as very small. She states she is not always adherent to her antiretrovirals because she believes that because she has an undetectable viral load she does not have to always take her medication.

*Rahvens, 32 years old, Site 1*

Rahvens is the mother of two children ages 9 and 7. She is engaged and living with her fiancé and children. Rahvens found out she was living with HIV when she became pregnant with her first child at age twenty-two. She shared with her fiancé her status the same day she found out and encouraged him to get tested, which he later found out he was HIV-positive. Rahvens is not sure who transmitted HIV to whom. Both of Rahvens' children tested negative for HIV and she states she was very adherent to her medication during both her pregnancies. Rahvens and her fiancé decided to keep their status to themselves. While Rahvens wants to tell her mother about her status she is nervous because she thinks her mother will tell her siblings. She also has heard family

members talk poorly about people that are living with HIV. Rahvens is also living with neurofibromatosis. Because of this disorder she is under the care of a genetic specialist. She states she and her fiancé are both adherent to all medical advice and medication. Rahvens is unaware of many community resources surrounding HIV because she does not want to share her status to receive services.

*Markel, 47 years old, Site 1*

Markel is a married woman with nine children. During the pregnancy of her 15-year-old (8<sup>th</sup> child), Markel met her husband. After she gave birth to her daughter, at the age of 32, Markel found out she was HIV-positive and that she had perinatally infected her daughter. She had no idea that she was positive and did not get tested for HIV the entire time she was pregnant. Markel's husband was with her in the room when she found out her status. Markel disclosed her status to all her children and has an open dialogue with her daughter who she wants to be careful in making decisions because she is positive and wants her to remain healthy. Her 13-year-old son is HIV negative. Markel believes in using protection to stop transmission of the virus. She is also very informed of community resources available to people living with HIV.

*Sharon, 39 years old, Site 2*

Sharon is a single woman with six children. When she was 37, she stated she was very ill and thought she had a cold that would not go away. She was eventually hospitalized where she went into a coma. She was awakened from her coma and found out she was HIV-positive. Sharon knows the person that infected her. She is still friends with him, and he has apologized to her. She says she forgives him. Sharon is still very ill. She recently returned home after being in a rehabilitation center for six months. She

had to learn to walk again and thanks her mother, children and grandchildren for supporting her.

*Hope, 28 years old, Site 1*

Hope is a recovering addict. She has been living with the virus since she was fourteen years old. Hope lives with her mother, step-father and brother. Hope does not have custody of her children. Her mother has custody of her eight-year old and her one year old is in foster care. Hope describes having a hard time with her family, who she says ridiculed her about her virus. When she found out at fourteen the provider asked that she call her parents. Hope feels like her mother told people about her virus and her family spread rumors about her. Hope feels like her medication is a constant reminder of her status. She disclosed her status to her sexual partners including her children's father.

### Results

From the line by line analysis of the first three interviews, 72 open codes were generated over the course of 4 months. See (Appendix A, Table 5) for the full list of open codes. Using constant comparison during analysis, these open codes were reduced to 48 codes, during axial coding, and the next six interviews, were collapsed into 19 categories (see Appendix A, Table 6) with the Glaser (1967) coding families (see Appendix A, Table 4). No additional codes were created, and coding continued with the rest of the documents until saturation was reached (12 interviews). In using NVivo, the contents of codes were consistently reviewed and compared through the verbatim narrative and color coding within the software. After open coding, using mind and concept mapping tools the researcher was able to connect related ideas emerging from the transcripts. A total of twenty-seven memos were also created for documenting thoughts,

concerns and questions that developed. During selective coding, the researcher continued to memo, run queries on words, make models, and discuss preliminary findings and visual represented the data to discover a new theory. Using NVivo to develop relationships and codes, the researcher was able to reference back to the narratives to reflect back on the participants description of their experience while coding and mapping. Four themes emerged from the data which provided insight into unintended pregnancy from the participants. They include: Resilience, Outcomes of Sharing Status, Sense of Protection and Pregnancy. Pairing of these major themes develop a theoretical model of unintended pregnancy among African American women living with HIV.

#### Theme 1: Resilience

For the women, learning about their HIV status was a life changing moment, met with despair, hopelessness and thoughts of their life ending. Every woman described moments of gloom once they were diagnosed which were later transformed to a will to live and to be well. Three sub-categories of resilience emerged from the interviews. See Appendix A – Table 7. Theme 1: Resilience Coding Table for a full list of codes within the category and subcategories.

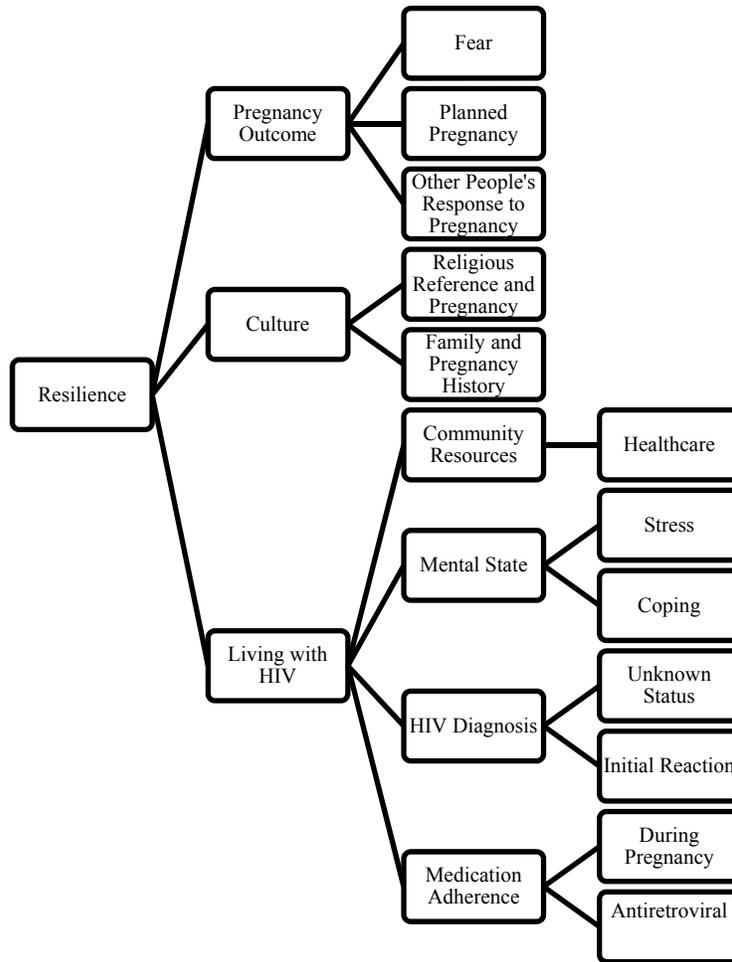


Figure 4: The following diagram illustrates the primary theme, resilience, and the secondary themes.

Living with HIV includes the women's thoughts about their diagnosis, health care as it relates to medication adherence and their mental health. It also includes their ability to make choices about their willingness to manage their health, access community resources, improve their quality of life and the lives they are responsible for. Culture includes thoughts and behaviors associated with religion, pregnancy and family history that were representative of hope in the lives of participants. Lastly, there were several women that were diagnosed with HIV or already living with HIV when they were told they were pregnant. Pregnancy outcomes were discussed in how women addressed their fear, the ability to influence pregnancy outcomes and other people's responses to their pregnancy desires.

#### *Living with HIV*

For almost all the women interviewed, living with HIV was a decision that had to be made. Each woman provided strategies of what they did to move from learning their status to a place where they wanted to live and be healthy. When the women perceived they were capable, they intensified their efforts at coming to terms with medication, overcoming feelings of despair and pulled themselves out of women that were newly diagnosed to women living with HIV. Angel provided an account of when she was diagnosed:

I mean, at first, it was hell. Uh, my first reactions when I first found out my status, I was in my prenatal care doctor. They told me I just blacked out, you know. I just was like, how, why, you know, how long, stuff like that, you know.

In this account, Angel needed the assistance of providers to share with her, her initial response and how she was mentally unaware. Her "blacking out" was associated

with crying, screaming and loss of control emotionally. Many responses from the women were of shock, disbelief and denial. Several of the women referred to their emotional and mental wellbeing after the diagnosis, where they experienced extreme emotions and questioned their mental stability.

... yeah, when I first found out about it, it was just like, Wow, I feel like my life was over." Felt like it was over. Um, I was gonna lose my mind ... I was going through a whole lot when I found out (Rahvens).

Sade's initial response was hopelessness. She shared, "Oh there's no hope for me, I'm gonna die". Marie's response was entrenched in denial, she shared, "at first I was in denial, and I was like, I'm gonna get retested, and see, you know, and I got retested a second time to see, um, would it say the same thing? And it- it did" (Marie). Shay expressed feelings of anger, "Um, well, at first in this, in the beginning, I was kind of mad. I started, um, I was, um, I was sad, and mad."

And how I got into the coma because, um, I have, um, HIV, but I never knew that I had it. And when I did find out that I had it, it was not too late though, but the symptoms started getting a little bad, I guess. I'm assuming (Sharon).

Three women admitted to using drugs recreationally during the interviews. No one mentioned the use of intravenous instruments. Sexual activity was mentioned by interviewees and was relatively the thought of how all the women were infected. Sexual history and the number of partners was reflected on when discussing the initial reaction.

Like, it had me thinking you know I mean where? How? When? Like it just had me thinking and I still think about this from this day, like how in the hell I got this, or, where did I got this, was I sexually active or crazy? Wasn't doing this or crazy. So, it's like my Mom had us in the house on a leash, like, it wasn't- I wasn't no wild- I wasn't, I had too many brothers, so I was too scared to even have intercourse (Angel).

Hope shared, “I don't know. Uh ... How ... Well, for me I don't know. With HIV ... How did somebody can do like, for HIV... For me, to get it, I don't know how I, I got HIV.”

Angel associated her positive results with something going wrong, “I don't know where it came from because his father, because my daughter's father is negative. He got tested umpteenth times. So, I don't know what happened. What went wrong. Did I get, you know, I don't know.”

And I, I just had a shocked look on my face, because I was mad. I didn't know who did it. But I don't which person it was, because I had too many men, and they, I didn't know who gave it to me. They didn't tell me.  
(Shay)

When I was nineteen. My mom was with me when I first found out, because I thought I was pregnant then...they gave me a HIV test too, and that came out positive. And my mom was crying, and I was, I was mad, because I didn't know who did it. (Shay)

Testing of sexual partners for HIV was not mentioned by any of the women. However, two women were told by their partner that infected them that they were HIV positive. Shana and her partner did get tested for sexually transmitted infections, however her partner mentioned later he was born with HIV. Shana continued to have unprotected sex with her partner and to get tested for HIV. All experienced a range of emotions, including angry, feeling ashamed and “stupid” (Shana). They shared blame for themselves and the other person. Sharon knew the person she was with infected her. She expressed feelings of forgiveness.

I had HIV since I was ... 17. Um, through, um, a relationship where the guy had it. He knew he had it. And we were together ... He told me, I think like the a- like the end of the first year that he had it. And then I went to the doctor and I had it. And, um, I've been coming to get care ever since then to- for healthcare. (Marie)

I don't know what month it was and I can't really remember the year when he told me, but he told me two weeks after ... I mean we'd been having,

you know, sex or whatever, unprotected sex or whatever, but he told me two weeks after we had sex that he had HIV. And I wanted to punch him in his face 'cause why you didn't tell me. (Shana)

I didn't know ... I didn't uh ... I didn't know that I was gonna get HIV at all. Um, knowing his status, I did get checked out, came here and got checked out and full too and uh when I ... I kept just-just getting checked out...Just kept getting checked out, kept coming out negative, until one day ... I went to the [clinic] 'cause I had an appointment and um came back positive. I was HIV positive...I didn't really expect it, but that was my own fault because ... Come on, you know about his status and you still continue to deal with having sex with him without using a condom, so young and dumb (Shana).

Uh, the guy that I caught it from, like we still talk. That's the one who just stand outside with in the hallway. I caught it from him, so it's just like, like we've ... we s- ... We're still friends. Like we still chit chat, 'cause it ain't nothing nobody can do. I can't get mad at you. Like I could beat the hell out you, dude, but, um, I'm not going to jail for him. And I'm, I'm serious (Sharon).

Like I'm ... I d- deal with it. Like we still talk. We still communicate. Like he'd go to our doctors with me. He already ... He already knew, because he's the one that gave the hell to me...when he came to the nursing home and, um, I told him, 'cause he ... 'cause he ... 'cause he was asking why I'm taking all these medications, just then ... there ... And, and I said, "You should know...like you should know better than I should know. And then went off a minute, then he's like, "Yeah." He's like, "I'm taking the same exact thing." He a good person though, but he and me know h- ... I forgive him though. 'Cause like shit happens. And like, um, even though I didn't want to though, but... two wrongs don't make a right. It's, it's a mistake. But a mistake that shouldn't happen though. But it's alright. (Sharon)

Women struggled with fear and shame resulting in thoughts that their partner no longer wanting to be a part of their life due to their diagnosis. Other women explored the possibilities of a disruption to their present relationship. Rahvens had the longest monogamous relationship of all the women interviewed. She described “losing him” and losing everything. Rahvens’ partner also tested positive soon after she did; she shared the pair spent years blaming each other for who infected who.

A life. I thought everything was over, like, when I first found out I was still ... I've been with my kids' father for 13 years and I thought he was gonna leave when I found out. I think I thought everything was over, like, life. (Rahvens)

Learning of one's status was described as shocking and every woman stated they were taken aback. For several of the women, they found out about their status while being pregnant. This news was devastating and caused distress, it also served as a catalyst for women to begin their journey of understanding and knowledge of medication adherence. All the women experienced a level of confusion about what HIV meant to them, their health and their partner's health, as well as their future relief and happiness.

Like when I found out I was HIV positive, it was after the birth of my daughter... So you know, my daughter had it- has it and me and her both have it. That was ... I-when I found out I had my daughter. My daughter was born premature. I didn't know we-I had it, and was carrying her. So, I didn't get treated for it (Markel).

The following accounts explore diagnosis of HIV while pregnant, "Pregnancy and living with HIV, like, when I first found out I was HIV positive was when I was five months pregnant with my daughter" (Rahvens). "Well when I was pregnant, yeah I found out I was positive... When I was pregnant, yeah. Yeah but my baby daddy don't have it" (Sade). "Well you're pregnant, and you're HIV positive." I said, "I know I'm pregnant." She said, "But do you know you're HIV positive?" I said, "No." (Sade).

### *Medication Adherence*

Because of the advances in medication, many women were reassured by providers that they can take medication and live a healthy life. Moreover, in the case of pregnancy their children had a great chance of being born healthy and uninfected. Their thoughts of despair changed over time and were replaced with the ability to live and take care of their

daily responsibilities and face stressful events. In considering their HIV and living well, all women referred to taking medication to be healthy. “That's the main thing, you got to keep them numbers, them lows, them CD4, then viral loads up. Once you do that, then you're, you know, you know, you got a chance. You okay” (Angel). “If you take, take your medication, eat healthy, you live a long life” (Hope). “I miss not near one. Mmm, don't miss no doctors appointments. Take all my medication” (Sharon).

You don't have to risk to give it somebody else and die. You have to take it 'cause you want to take it right? You want to see a future. You have to take your medicine. You don't, you don't see a future. You don't see your kids. You don't see nothing. (Joy).

Turning points occurred with the women when they started to recognize their ability to establish a routine surrounding their medication. “[Take medicine] Every day. The same time” (Rahvens). “As long as you're taking care of yourself and as long as you're taking your medicine every single day and as much as you can” (Shana). “I've been good. I've been taking it for many years, so um, I don't have a problem with it” (Markel).

Pregnancy influenced many participant's adherence to antiretroviral medication. Women described success with taking their medication and after experiencing times of forgetfulness and/or frustration with having to take their medicine. Marie shared that taking medication was “easy” because she did want her child to be infected. Providers were consistent with their message to participants that a HIV positive mother does not necessarily mean a child will be infected.

Um, but that was easy because you know, you don't want this child to have what you have. So it was really easy. Like even ... I-I'm not- I don't take my medicine faithfully like I'm supposed do everyday because I'm forgetful. And they're working on giving me monthly shots so I don't be so forgetful (Marie).

But when I was pregnant I had to be, um, consistent with my pill-taking because I did not want my sons to come out- I didn't want them to live with that. So it- It gave me- It-It motivated me to take the more for them, for their sake (Marie).

A lot of other people was talking to me, "Well, you know there's pills you can take, and your daughter won't- it won't go, um ... it ... I can't even get it out. Your daughter won't have it when you have her and, yeah (Rahvens).

I was two months. So they got me on medication, and I took my medication. So had one of the doctors, she had um, she had given me new medic- well, they changed my medicine 'cause I was pregnant too. Once they changed my [medicine]. My mum said, "I'm praying that the baby come out healthy, as long as you take your medicine, you know, because I know a girl that had HIV and she took her medicine, and her baby didn't come out with it." So I was like, "Okay, okay," and then my cousin, he was like, "Well I know this girl, her mum HIV positive and she says she's HIV negative (Sade).

You gotta make sure you take all your medicine. If you don't take your medicine then you're thinking like oh my god if I don't ... If I miss this one dose, if I'm giving it to my child. It's like, it's like a lot of things for that. Like you don't get cut, you gotta be very careful (Joy).

I know that when you are pregnant, it is important- It's important if you're not pregnant, but it's- It's important when you are, so that, um, you can protect your child, and your child, you know, if you don't- Of course, you don't want your child to have, um, HIV, so that's a way of making sure that they don't have it (Lilly).

Cheryl had four pregnancies while living with HIV. There is HIV medication women can take during pregnancy, however, it still came with side effects.

Mm-hmm (affirmative)- And sometime I missed doses. Sometime I was, like I said, sometime I threw it up and I might have called the doctor. And he said, "Well you can take it again, but we don't want you to take it again because you might have did get some of it down if you didn't really see the pill come up." But. So it was like, so during that time, it was kind of like scary thing. Because it was like, "Okay. I got my medicine." But sometime I was sick and I didn't get my medicine. So it was like. And then you got to give the baby the medicine after you have the baby. You got to give him the medicine (Cheryl).

In recounting their experiences, participants described their reasoning for taking their medication as prescribed was very clear, while pregnant. They evaluated the risk of having a child born positive and the shame they would feel if the outcome of a pregnancy was positive. The consequences of not taking medication changed in varying circumstances and the women described their nonadherence. Angel shared that her viral loads consistently remained undetectable. Therefore, she took antiretrovirals during her pregnancy, however, decided after her child was born, “I took myself off my medication after I had my child...because my viral loads were so undetective” (Angel). Shana offered the ability to recover in the event a dose is missed. She shared: “if you do miss a dose, it's not the end of the world, as you know. Just make sure you remind yourself to keep taking it and, you know, stay on track with it”.

The risks of not taking medication did not appear as strong as it did when a woman was pregnant. Although all the participants acknowledged taking medication would affect their wellbeing, there was differences in the way each discussed adherence, trust that the medication will work and side effects.

There will be sometimes I will forget to take medicine with the ... And I just would let them know I freaked out, you know, I stopped taking the medicine, I forgot or I wasn't home for a long time and I didn't take any and it still was good (Angel).

Maybe take your medicine, you stay undetectable. But sometimes people take medicine, it don't work. So sometimes I wonder like is the medicine will always work or is it going to stop working...Ah, wondering sometimes if the medicine just gonna stop working and what, they not gonna have any medication to, you know, help. Even though they keep saying they come out with new medication, but who is to say that the medication will actually physically work? You know, some medicine work for some people. And some medication doesn't work for some people. Like everybody can't take the same thing. And everybody body is different. So I mean I just be wondering (Cheryl).

Uh, well. Um, there's certain medications that um, that um ... I heard of a having a birth defect. It was one medicine Triumeq that I was on that um had a birth defect. They found a birth defect in it so if I want to still be on Triumeq, gotta be on birth control. And um I switched and everything (Shana).

Some women described how taking medication everyday was a reminder that they were living with HIV. While taking the medication has its benefits, a majority believed that this was the greatest change associated with living with HIV.

Um, it's not that hard really. I'm just like anybody else. Um, I have, I, I have problems, only problem I have is when it's time to take a medication. Um, I don't like taking medication. I think it's because it's a reminder constantly (Marie).

To sit here and be like, "Okay, I gotta take my pills every single day." And you gotta remind yourself why you gotta take it because it's like uh, It's like a mind habit. You gotta keep taking it, you can't give up now and not take it. It's stressful to remind myself I've gotta take it, but at the end of the day I take it anyway (Shana).

Joy stated, "Just, you know, I know what the medication is... You know what I mean, It's a reminder". Angel felt the medication was associated with her mood, "Yep. Um, it's just, I will make it my last, because I feel like me being back on that medication give me back depression and put me back into a dark hole I was in before."

Participants descriptions of their experiences with medication adherence and pregnancy suggested that the fear, despair and anxiety related to having a child decreased during multiple pregnancies. The skepticism of medication working, confidence in their ability to take medication, and having a HIV-free child inspired and empowered them. Rahvens shared, "the second pregnancy, I was happy, you know, because I knew what everything, um, that I can- I take my pills and she won't have it. She don't have it. Um, that was exciting." Markel shared similar thoughts, "Yeah, it was-it was okay because I

knew, I'm saying, I knew what I had to do. I was more aware of what I needed to do to keep him safe.”

But um if, if um, if your medication is uh willing to help you do everything and you do get pregnant and your medication copes with that and your baby comes out fine, that's a wonderful thing. But the medication they tell you that it's a birth defect, uh I'd advise you to like switch or something, if you wants to switch, it's up to you. But um, I mean, yeah, medication and pregnancy And that was like, uh, I was like, and I would, I would try to take the medicine if I ever got pregnant (Shana).

Yeah, there's still, um ... You just are 'cause you know it's like it's- It's like the- I don't really understand how the pills work from protecting the babies, so there's still, um ... You're still scared. 'Cause I think, um, both times I-I had to find out I was pregnant within like two months, so it's that two-month time that you were pregnant without any medication for the baby, so ... I was scared. Um ... But after my first son and I went through with him, I was- I was less scared with the second one (Marie).

My boyfriend asks that all the time. What if you get pregnant? What if you get the baby? I sat him down like the baby not going to get nothing to be honest with you 'cause if I take my medicine, that will keep my vital up, so the baby really not going to get nothing if I take my medicine, so we'll be all good (Joy).

### *Mental State*

Thinking about the challenges of living with HIV among the women was described as “dark” by several of the women (Angel). But knowing that they can be healthy inspired and empowered them, especially with overcoming learning about their status. No one wanted to stay in the place where they were when they were diagnosed. Several of the women reflected on the complexities of the diagnosis with medication, treatment, diet, exercise and committed to staying healthy, this included their mental state. “I adhere to treatment, eat right, exercise, and see my doctor regularly”. Angel reflected on her journey to emotional wellness:

I already suffer from depression, so at this time I'm ready to kill myself 'cause I don't want to live with this. It took me six years to really like

overcome it, you know, deal with it. I've got 302'd, I've slit my wrists on all this. Like, every day I used to go see, I used to wake up, I don't want to wake up, I don't want to wake up. I just want to die. I just, that's all I wanted to do. So that's just all I ever wanted to do is just, do something crazy to myself because of my status. Before I'm where I was at today I wanted to kill myself (Angel).

I was kinda depressed. I think I was postpartum during my pregnancy, well all my friends said I was depressed (Cheryl).

I had a hard time living at the beginning. I had a hard time dealing with it, because my family had put me down, my mom's side of the family had put, my nieces were putting me down about me having HIV (Hope).

Some of the women discussed how they had to face traumatic experiences during their journey to wellness that also helped them to adopt a resilient approach to manage living with HIV. Hope shared, "See with my mom, wow ... My mom has, I don't know how to say it, put me through a lot." Joy stated, "Then I'll be like sad a little bit. It's just like, just like both at the same time. I just lost my mom like not too long ago, like a year ago." Additionally, Marie concluded, "I have a hard time since I was, um...like, dealing with my children because I have things going on with me, um, because of my upbringing." Markel also shared her experience with depression, "Death depresses me. They took me to a whole different dark space, when I found out I was HIV positive. You have to be really be strong for it. You really have to." Rahvens also shared, "Like, I was thinking about suicide and all that, but then I'm thinking, "I'm pregnant."

Knowing that you do have it, you don't have that normal life that you did have, like, this ... Hmm. I think way before I was, like, before I was-knew about it, before I even had it, I was going out more often. And knowing that I have it, it's just like I don't wanna go out no more, like, 'cause I have it. Like, going out with friends, um, family members when they go out, go out with them. Anywhere, like, anywhere. Like, to the movies, to the beach and stuff like that. It's just like, "Wow. Should I be doing stuff like that?" I don't know why I feel like that (Rahvens).

Sade discussed reflected on her experience, “It make- it make- I got tough skin, it used to make me not eat and depressed.”

You can't just cry about it and pout all day because that's not going to make anything better. Just be happy that you still alive. Be happy that you're not dead somewhere, you know. It's not a death sentence, death sentence (Shana).

Sharon shared, “Like and I just dealt with the situation. And I can't let it beat me.”

And, um, uh, 17, I became, I became diagnosed with schizophrenia, depression, but it's called schizo-effective depression. When I was 19, all the way up into, like, my 20s, I was thinking about, like, uh, 20, 20, 22, oh, let see. Um, I said, til 19 to 21, I was mad I had HIV. I said I, towards the end, like, towards the end of, um, I did, and I, uh, um, the year when I was, like, 21, I started thinking those good things, and I've been good and glad ever since then (Shay).

There were several women that experienced daily stress but exhibited skills in managing their ability to bounce back from stress. Several of the women provided a positive outlook and was able to assess their own positive characteristics and resources. With stress, the women were able to describe in detail and severity the source of their stress and in detail their optimism, spirituality and purpose in life. Below are examples from Angel where she talks about her stress and her coping.

So, yeah, I'm just dealing with that, just my taking care of him [toddler son]. My daughter died, it'd be- it's a year. So, I've been dealing with the not burying her dad two years before she died. He got hit by a train. And the year before he died, buried my dad, so ... yeah (Angel).

I try. It's a struggle every day, but, you know what I mean, I look at him [toddler son] and I'm a fighter... I can do it. I buried my daughter, dressed my daughter, did her hair, pregnant, everything pregnant. I had to get the last moments. I had to. Didn't nobody ... My daughter six years and nobody never did her hair but me. And like I tell people, you know, you don't know when nobody's going through until you hear they life story. Walk a mile in my st- shoes, you won't survive, you won't last. I buried five people back to back within two, three years apart. All of 'em was close to me. My dad, my grandmom, my daughter, dad, my daughter (Angel).

Like I said, you know, I just knew my day was coming any day. That's just how I looked at HIV when I found out, I was diagnosed. I was just looking for death. There was just death coming my way like, oh my God, it's just my time, it's my time until I really looked up and learned what HIV was really about. And that made me change my ideal of life, you know what I mean (Angel).

Everything stresses me sometimes. Sometimes when [daughter] can't get his self together in the morning, I be stressing. Sometimes when I be like, Oh my God. I gotta go to his school again. You made me go to ... I be like, Oh, Lord, please help me." And sometimes I snap on my son and be like, I be like ... He was supposed to, um, he missed his interview with UPS and I was like, Well did you try to reschedule, cause on the thing you can like click if you miss it to try to get another interview. He like, I'm a do it. I'm like, Well I don't know who y'all people think gonna keep taking care a everybody in here (Cheryl).

Pertaining to the HIV part I wanna try to keep that as healthy as I can. Well, maybe you don't think that, but in the back of my head I don't know how long a person wanna live, but I wanna live as long as I can (Cheryl).

Other respondents shared, "Um, so many doctor's appointments [stresses me out] ... I'm just like, I got this, you know, for this next nine months. But it's like a concern and they're pushing you (Marie). Coping skills were demonstrated in several responses. Maintaining emotional wellbeing and adjusting to stress caused by daily life or HIV was approached differently by all the women. Some were successful at self-talk, creating boundaries with dealing with others and seeking health professionals.

You can deal with it [HIV], learn how to cope with it, and learn how to accept it, and you'll be better off. You know, I was like, It's-it's like a disease, like cancer. You live with it, you deal with it, you do what you do." And I had to really look at how like, Damn, my dad was paralyzed since we was kids. My dad lost both of his legs and my dad lived a century. He worked. He went up some steps. He cooked. He did everything for his self, and that just made me even stronger, like I can do this. It aint nothing. And that's how you just got to look at it. Some people-some people ... We-you got to come out of that. You really got to come out of that. You got get help for it. You got to look past it [HIV] (Markel).

So, after that [blaming each other for HIV transmission] when we talked- really sat down and talked together, we ch- it changed and we, just like we can't be fi- fighting and arguing anymore (Rahvens).

Um, I go to therapy, I talk about stuff, and instead of crying about it and feeling bad about, Oh, it's another year of living with it, celebrate it, don't celebrate it because, Oh, yeah, I've got HIV! No, celebrate it because it's part of you. It's you (Shana).

So you know, that's what I had- that's the price I gotta pay to be me. And I said okay, I'm gonna have a life well don't kill me, only help build me, it makes me stronger. Thanks for the favor, it only made me strong. Go ahead and laugh (Sade).

Like some days I was feeling better. Some days I wasn't, but came up on a year. January stuff, that's when everything start going downhill. And what happened is when everything just hit the ceiling, it, it wasn't no more I could do about it. I wasn't going cry about it. Like sometimes, like now, like I share tears, but yeah, that's not me. Like I just suck it up. Like can't take it back now. Um, I j- ... I was living my life. Care to live for. I care to live for. So I gotta keep it doing what it doing (Sharon).

I started, uh, telling myself good thoughts, and then I just got happy, and, and, um, I just been, uh, happy and glad ever since-When I started having good thoughts about it, though, I was like, I, I started listening to, um, good thoughts, uh, over the top of my bad thoughts, like, uh, what did I say? Like, uh, that even though people with HIV, um, got the [inaudible 00:18:12], like, they can still live long (Shay).

### *Family Size*

The historical context of religion and family size as it relates to past pregnancies, family size and alleviating anxiety stress within a woman's family and earlier years are important for understanding beliefs. Many of the women shared information about their family and background which provided insight into their values, fears and views.

Resilience is determined by a range of cultural values. Thus, resilience has important personal, intimate and communal dimensions that exceed wellbeing. The women talked about the role of childbearing in their lives and the lives of loved ones.

I just, from my experience, from knowing people that have unexpected pregnancies, it's just like, the world's coming to an end. For a lot of females. Oh, I'm pregnant, oh my God, he not gonna stick around dah dah dah. 'Cause it wasn't never planned. You can't have a baby and both parties not agreeing to it (Angel).

I don't know people that plan- I don't know anybody that planned (laughs) on being pregnant. We just had babies. I think in our [black] community it is. I don't- It's rare in our community that we plan pregnancies. Like I- I've never heard of it. So it's just normal in our community [unintended pregnancies], I think. Um, the black community. Every-everybody around me. Um, I guess that's what society says. That's what the community says, anyway. The Muslim community. And it's like- I've never- the Muslim community, the black Muslim community. I have not always been Muslim. I've been Muslim for 12 years now, and I've never seen so many women with so many kids (laughing) before then. I'm dead serious, I'm talking like up to nine kids. we're told as Muslim women to- we're supposed to have a lot of kids to make the Muslim community bigger, hence why it's so big in Philly, but, okay, you're having too many kids (Marie).

Angel shared, “Yeah. But before her I was always with somebody else kids and nieces and nephews, is 36 of them [from siblings]” (Angel). Marie stated, “But my mom has nine children... And she-she ain't planned (laughs) none of 'em. (laughs). My mom became pregnant nine times, but she didn't want to be a mother” (Marie). She also provided insight into her siblings experience with pregnancy.

[My sister] She got pregnant- the last two times she got pregnant she left both those babies in the hospital. And I was, um, disgusted. Because I'm like - okay, you not only did it once, you did it twice. I'm talking about with then like the next year, like it was very close together. So, you got pregnant back to back, by the same man, and you knew you didn't want to have any more kids, but you did, and then you carried the kids for nine months, and then you just left them in the hospitals. So, it's irresponsible (Marie).

Sade shared her family background, “My mum got 12 girls, and my daddy got five boys. She had 'em all natural. Pushed them all out... And it's funny because my daughter, and my little sisters are the same age.”

Mmm, my son ... My 23-year-old got two kids [two women pregnant at the same time]. He got a, a one year old, and an eight-month-old... My son, T, got a baby on the way. Fourth grandson. 'Cause it's another boy (Sharon).

Regarding parenting, Sade was the only women to reference how her mother and grandmother played a role in learning how to become a mother and the tasks she had to complete.

I was ... Well I was young at the time. I thought I knew it all, but I didn't know it all. I had to have help from my mum and my grandma, but I used to hate when they be like, you're making the bottle wrong. I used to hate that. I will hate them out here all day talking about, I didn't know nothing. So at first I didn't want their help, but then I- I accepted their help because I wanted to be a better mother. So I took some of their advice, not all of it (Sade).

Some of the advice I took that was gonna better me to be a good mother and care and in loving my child like I'm supposed to 'cause I was changing the diaper wrong all day, but my mum was like, "Oh my God, what is going on?" So she ... So my mum would make the bottles and then she's like, "I'm gonna teach you how to make it, then you better make it. Little bit of cereal, then you know, three scoops of milk and shake it up (Sade).

### *Religion*

Religious references were made by most participants. Participants often discussed their health, happiness and personal circumstances in the context of religiosity. Many of the women placed value in developing a sense of purpose and understanding of their circumstance, their drive and desire to move forward despite challenges, setbacks, and hardships. Several women provided insight into how religiousness is a significant

resilience factor for them as they dealt with difficult times and helped them adjust and face major life stressors. One respondent described her experience:

But I said you know what? I have a God. Where there's a will, there's a way, go pray. I pray, I don't let people take me off my square. I don't let people make me depressed. She hurting my feelings, I hurt her feelings right back (Sade).

Sharon shared, “But I told them the devil's a liar. So I, I had to bounce back.”

Angel described pregnancy as, “It's a blessing [pregnancy]. And may at first, I thought, like, I couldn't conceive, for my daughter. She also referred her perception of her home as it relates to religion, “Where I was living it was just negativity, barely alive, no happy spirits like demons was-was running around this house” (Angel).

I thank God for that, 'cause that will be like, that would've been a real curse. Oh you gonna die," that's the first thing she said, and I stopped hoping a little bit then I read my bible and something said, "You're not gonna die (Sade).

Several women mentioned children in the context of a blessing. Shana shared, “And I do think if you believe in God and, you know, if he gift you with a child, don't regret it. Make sure you take care of that child because you never know”. Another participant stated, “My kids, and knowing that I, HIV, and that they don't have it, is a blessing from god though. But I don't want them to get it from nobody else” (Hope).

### *Pregnancy Outcome*

Resilience during pregnancy is exhibited with the ability to cope and remain optimistic during adverse conditions, to overcome difficulties while maintaining psychological and physical health. Several women explored the psychological aspects of

HIV during pregnancy and the possibility of a planned pregnancy, fear and other people's response to pregnancy. Many of the women maintained a positive outlook and celebrated their child was negative. For the women who experienced a pregnancy and their child was parentally infected the role of resilience was explored. Women also shared responses that other people had about the possibility of them planning and becoming pregnant.

They thought that she was going to be like a nine-pound baby, but she was only six pounds. She was a tiny little thing, like tiny. So I'm like, "Oh my God, you need to tell me." I've been carrying around this big old belly, and all this full on these legs, and you just like- (laughter). I think she took her last ... I believe she got lost her last test, so she was fine. She wasn't positive or anything like that (Cheryl).

Uh, she [my mother] had questions, but then she had thoughts. She was more so concerned about my health, and then she was concerned about her grandkids, like, you know, what could possibly happen or, you know, if they would be, you know, positive. My concerns was they would be positive and die. You know, that's what I actually thought as a kid (Cheryl).

She's 13. She has it. I didn't know we-I had it, and was carrying her. I think I probably was depressed with my son. I was depressed for a while, well before I had him. After I had him, I ... the depression went away. But, like, during my pregnancy, I was just more concerned, like, "Oh my God. Is he gonna die? Is he gonna die?" You know? I was more so worried about that (Cheryl).

Fear or "bring scared" that an infant would be perinatally infected was a significant finding that all women expressed. For several of the women finding out their status during pregnancy lead them to reflect on common belief that their child will be born with HIV and expressed fear. When asked the respondents thoughts about being pregnant and living with HIV, several women shared the same feelings. Hope stated she was scared that her child will have HIV. Rahvens shared she was scared as well. Marie offered her thoughts about delayed treatment while pregnant.

[Sacred] Yeah.... You just are 'cause you know it's like it's- It's like the- I don't really understand how the pills work from protecting the babies, so there's still, um ... You're still scared. 'Cause I think, um, both times I-I had to find out I was pregnant within like two months, so it's that two-month time that you were pregnant without any medication for the baby, so ... I was scared (Marie).

Each woman expressed different expectations regarding pregnancy and parenting that are often rooted in their community, family and culture. These norms and expectations affect individual reproductive behavior, pregnancy desire, perceptions of pregnancy, other people's views, and common characteristics of all the women. Angel, who found out she was HIV positive during a prenatal visit, planned her first child and her second child post learning about her status. Marie had all four of her pregnancies after she learned about her diagnosis and planned none of her children. Joy believes there is no such thing as planning a child, that the act of a child being conceived just happens. Women with multiple children discussed how some of their pregnancies were planned which highlighted financial goals, personal goals, communication with the sexual partner and assistance with pregnancy. The women described their thoughts on planning a pregnancy:

Both of my pregnancies is planned. I had a set goal. Prime example, I wanted to get pregnant before Christmas. It didn't happen before Christmas, happened two, three days after Christmas. So, we planned that pregnancy. We planned the way- we planned was it gonna be natural, we planned (Angel).

it [Planned Pregnancy] would be two people that sit down and actually say, you know, we wanna have a baby. You know, when should we start? Like, you know, sometimes some people plan it like, we're going to have a baby 2000 and- say 2019. We might start in May, cause we want the baby- you know, I hear people say, "Cause we want the baby to be born in the wintertime", or "We want the baby to be born in the-" you know. They make preference when they want the baby to be born, but sometimes they come before then. They come early. Or they come when they feel like coming (Cheryl).

I think it's better if you do plan. You sit down and say, well we wanna do this, cause this person probably works this time, and we need to know who's going to take care of the baby, so one of us can go back to work, cause we both can't stay home, cause somebody gotta pay the bills (Cheryl).

It would be like ... Okay, 'cause I'm in school right now, right? I would be like, "Maybe after I finish my Bachelor's I'll have another one." This is a very hypothetical situation 'cause I don't want no more kids. Or after we owned a home or got a bigger house I would put it on- I would make it like really outlandish to where (laughs) I-I wouldn't do it. But I don't know (Marie).

I think it's kinda backwards because we should plan because our finances are somewhat tight, but the rich plan and they, like, you know ... They plan more so, but they could just have as many babies as they want, but they are still thought out and planned or, you know, restrict themselves and we don't. And that's why we are restricting it (Marie).

You planned it. You deal with it. That's how I see it. If that's what you planned to do, you have to be stand up to the plate of what you planned for. This is what happen when you plan for stuff. I don't see no other way. I've got nine of them, and I aint plan all of them, but I planned a couple of them. You know? But I was just blessed with what I had. I planned for the first three. The other ones came along (Markel).

Well, a planned pregnancy is like a pers- well, two people who are one person, just plan on getting pregnant, and it just happens. So in order for you to plan to get pregnant, you got to get off Depo, you got to be having unprotected sex (Sade).

Um, that's that is saying if it's very planned and you really want to have a baby and you know it's the right time to uh have a family and settle down, whatever. I think that's really good and it's beautiful. It's a beautiful thing (Shana).

Uh, mmm, like ... probably like t- ... mmm, three. Probably like three [were planned]. Well whenever it was, I, I thought I couldn't have kids, so I used to go to the doctors, whatever, get, uh, um, ovulator testers, just the, the ... Yeah, I went through the, the, the whole nine yards. Which is where I got ovulator testers like he went to the doctor's meeting, got his sperm cell count ... counted. Just under 30 (Sharon).

Family resilience and the ability of a person to share information with their family group can help the family member adapt to challenging circumstances. Women who are

living with HIV often encounter multiple stressors. Women explored how they think and what they experienced when they shared information about their status and/or pregnancy among their confidants.

Nothing, it was just my mama. It's just, the only people that know is my immediate family. Which is my mom and my sisters and my brothers and my partners. That's it. No cousins, aunts, uncles, nobody. Uh-uh (negative). My mom, every, the whole family was happy [about pregnancy] (Angel).

Cheryl's sharing was met with the reality of her housing. She shared her mother's response, "She had her moments too where she would get mad at me [mother]. She would be like, I don't know where that baby gonna sleep. That baby not sleeping in my room. Yeah. She had her moments". Sade, reflected on her feelings with sharing her pregnancy with her grandmother, "And I was scared to tell my grandma because my grandma, I was like eight- 19, going on 20. But my grandma went off. She's like, "You're gonna get an abortion and that's that." I said, "No I'm not." Lilly and Joy do not have children, however both have people in their support system who they believe would be happy if they found out they were pregnant. Joy shared, "They'd [Boyfriend and best friend] probably be happy [if pregnancy occurred]. He'd probably be happy." Lilly responded, "I actually, you know, the conversation that come up with it, and she [my mother] would be happy. Like, she would be really excited.". One responded connected the possibility of pregnancy with becoming a mother.

Respondents were also confronted with the family members thoughts of their pregnancy and HIV status. Hope explained, "They thought my kids was going to have it. I felt bad because they thought my kids were going to have it because I

have it. didn't, didn't have it, then they were shocked at why.” Marie addressed her family’s possible questions as an elephant in the room.

They like- they're like scared to say something. Or, I guess don't know what to say, or don't wanna offend. Because, it's like, um...how you know the baby gonna be alright? You know? Or they'll ask that question, or they'll say something like that, or, um...or, my family are like the kind of- if they don't say anything, they don't wanna offend you. So because they not saying anything, well they think they're going to offend me by asking me, you know, are you taking medicine? Is the baby gonna come out with it?...only one I had to talk to it about was my husband. I didn't have to talk to anyone else about it (Marie).

The emotions exhibited from discussing their initial response to learning about their HIV status to any change in their demeanor when discussing the progress each woman made in taking control of their health were observed and noted in field notes. When asking about their status, living with HIV and discussions of family history some of the women cried, took moments of silence and the theme of resilience followed where they would reinforce, they are past the point of shock and despair and on a journey to live a fulfilled life. Figure 4 illustrates the major paired theme of resilience: living with HIV, culture and pregnancy outcome are primary themes where each have several secondary themes. Resilience, as the ability to bounce back and cope, is the first component of the developed theory.

## Theme 2: Outcomes of Sharing Status

Sharing one's status occurred in several incidences. Women were accompanied by loved ones when they learned about their status; they also reported sharing their status with confidants and other people disclosing their status with and without their permission. Several of the women shared what shaped their decision to share their status and discussed feelings of anxiety related to stigma, extreme fear that their support system would change, and that HIV disclosure could cause more grief, criticism, judgment and harm than good. See Appendix A – Table 8. Theme 2: Outcomes of Sharing Coding Table for a full list of codes within the category and subcategories.

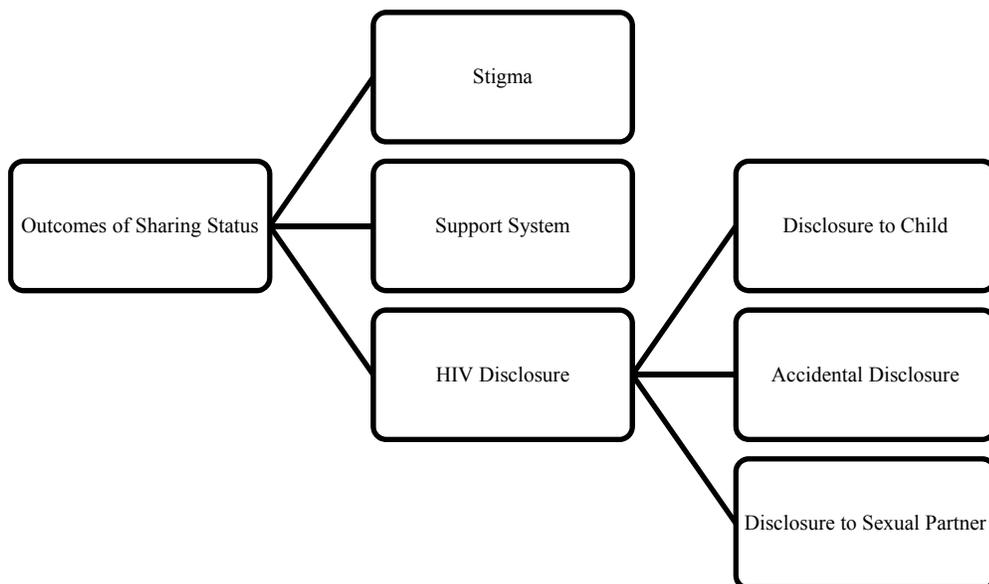


Figure 5. The following diagram illustrates the primary theme, outcomes of sharing status, and the secondary themes that are separate which are stigma, support system and HIV disclosure.

### *HIV disclosure*

HIV disclosure had significant findings as it related to the women's ability to discuss contraception, including negotiating condom use with sexual partners and weighing the possibility that they may be abandoned, experience domestic violence or lose social support. Angel found out about her status during a prenatal visit during her first pregnancy. She shared her status with the father of her child because she thought he possibly had HIV as well. Angel's second child's father found out about her status during delivery of their son, where he looked at the name of the medication she was taking. He later tormented her where he intentionally told Angel that she infected him, only to share he made it up. This left Angel in anguish and questioning who her support system was.

As time went on, I didn't tell no one. Just me and my- my boyfriend. It was just her dad. He know. Well, of course, my daughter father found out. But it took me almost a month to tell my mom. I told my two oldest brothers first..., I told them them two days later. On my dad's side. Then a month later, I told my mom and dad. And my mom had all her kids want to come together and talk about it and then, right then and there, I just blacked out. I just didn't, just didn't want to talk about it. I just, it was fresh to me, and everybody wanted to talk talk talk talk talk (Angel).

He lied about having it at one point and you can't play like that because if it's to the point that I was where I take my own life because I messed your life up...at one point he told me he had it. He went to the doctors, you know I mean but would never pull ... could pull paperwork...He was so sincere, serious about him telling me this and I'm just like no way because I've been with my daughter father for nine years...He was just rolling with the punches... and then one day he just told me, he was like, "I Lied" Why? Did it make you feel bad? Would you even feel bad if I would have killed myself because I would never want to do that but like I tell you, leave me, Leave me (Angel).

Some women only decided to tell their parent and significant other about their status. For Cheryl, she received a call that the doctor had something to tell her. She knew that it must be something about her pregnancy but did not know it was her HIV status. Prior to returning to the clinic to receive news that the provider said they cannot share over the phone, she called her mother to receive the news with her.

She's the only person [Mom] that, besides, you know, the father, that knows I'm HIV positive. Well, my mom was actually there at the clinic, so she had them test me, like, two times, three times. I don't know how many times I got tested, but it still came out to be the same thing. Uh, [my partner] probably like a couple months- [My Mom] she'll take it to her grave. Yeah. You could tell her anything. You could talk about anybody, which she really don't like you to talk about people, but just saying, if you wanted to vent to her, she is there to listen. She doesn't really judge at all. She just listens (Cheryl).

All the women described disclosing their HIV status as stressful and unpredictable given they don't know how people will respond. Some of the women made it very clear that every sexual partner they have, they disclose their status, reinforce that if contraception is not used they are not to blame for transmission and the majority discussed having unprotected sex since their diagnosis with partners who were unaware of their status.

Some of the women feared facing a negative reaction to disclosing their status. Women described trust as a major component of sharing their status and time in a relationship with a person. Sade believed her mother told her family and shared that her mother's betrayal was hard to deal with.

Ah, I probably say ah, probably my children [I will not share my status with]. Because it's really nobody in my family that I talk to besides my mother. And I have younger siblings. And I, yeah. All my siblings is younger than me. I have one sister and three brothers. My one brother is locked up. And I have two, two brothers. But other than that, my mom only had one brother. And her aunts are old. So for me they're like ... Because I wouldn't want them to be trying to worry about me, worrying about if I'm gonna die or XYZ gonna happen (Cheryl).

I literally told without my family...two of my good friends and my boyfriend. I didn't tell anybody that I like socially know out of life 'cause I see how people act. I'm not going to tell you what I got and you act a whole different way like ... I told them when I know it was time like I felt like I know you're going to be there, my lifestyle, you're going to be there forever. Like we don't talk every day but I called them, they'll answer my phone call no matter what, so I know my thing is with them for life (Joy).

I told my god sister. This was about, like, four years ago, I told both of them around the same time. They both seemed to be okay with it. Um, they still treat me just how they was treating me before. No different. I think I knew my boyfriend for a couple months. Like, four months, I believe before I told him. I knew my god sister f- Hm ... I believe 12 years (Lilly).

I do have friends that I knew for a long time, but I wouldn't ... I wouldn't bring up my status. Even though I feel like, you know, I do trust them, I don't ... I wouldn't trust them with the information not because they would go tell people, but because I feel like they would- They would either, like, act different. Like, you don't know how they would react. Hopefully it's not a bad reaction 'cause there's some crazy people out here (Lilly).

Yeah, [I told] everybody now...maybe a couple months. It took me a while before- I didn't tell them right away. I told my sisters and, um- I told my sisters, like (laughs), we was walking down the street, I just told them randomly. Like, I don't why I did that, but, yeah, I told them- I told them like a couple months afterwards (Marie).

Well, my sisters and them knew from the beginning. Right after my daughter was born, my family knew. And my husband, and then, you know, my cousins and all of them. They all knew. Like we are-we are a close-knit family, and if-the funny part about it is because, (coughs) when I told my cousins and them, and it's funny because my cousin Aaron, he lead me to that, and I told my cousin, Aaron, all these years, I never knew that's what his mom died from (Markel).

A few people that I could trust. A particular friend that I thought I could trust betrayed on me and told my business to somebody and I don't really appreciate that. And I had another particular friend that I had in high school betray me too. Talked about it on Facebook (Shana).

Rahvens found out she was HIV positive while she was seeking prenatal care. She and her partner both tested positive and both agreed they will be the only two that knows about each other's status, this is the decision that her fiancé made.

No. He wants to keep it between me and him or in- in doctors, you know. I've been so close to telling my mom and that's about it. The only person I know I can tell is my mom. But, me thinking that she might tell my brothers and sisters and then that's how it will start spreading (Rahvens).

While Rahvens was able to disclose to her partner the same day she was positive, not all of the women took such measures. Rahvens and her fiancé both are living with HIV, however, her second pregnancy occurred because they both were drinking alcohol and “things got out of hand”. The ability to negotiate contraception, discuss PrEP and decrease risk because of HIV disclosure was explored. Hope shared she had a hard time telling her child's father about her status, but she had to tell him. Joy provided the history of her relationship and her trust in her boyfriend after sharing her status, “I known him for, going off and on for about four or five years that he know the whole time. So, he didn't get up and leave. He's still there.” Lilly and other respondents shared their thoughts and experience about disclosure.

I told, um, a ex, um ... He's not my boyfriend anymore, but, um, I told him about it. He was okay with it. Yes. I feel like, um ... I feel like anyone you're having sexual experiences with, regardless if it's oral, or, um, intercourse, I feel like they should know, um, because, you know, everyone should know. Um ... It is a little harder to ... I mean, you don't know when to bring it up. Like, when I, um, when I told my ex, I didn't tell him until after we had sex. Um, like, probably two months into ... To having sex. I believe it's [to tell a partner] very important, but it's just ... I feel like the comfortability when you're- When you're comfortable (Lilly).

I told my husband. My husband wanted to know because of my daughter. So when I told my husband, you know, I met my husband when I was pregnant with my daughter. So, you know, when I told my husband, my husband was like, Oh, you know, that don't change nothing. You know that aint nothing (Markel).

So he was like, "You talk about I have this," yeah 'cause I thought he gave it to me, but he didn't give it to me. I don't tell my status unless I'm in a relationship... And when people come to me like well, he must got it too, because the person I was in a relationship with, he didn't wanna use condoms. And gotta tell him, I'm telling you I have HIV, you don't wanna use condoms? So it was his choice. I gave him a choice (Sade).

### *Support*

Support from family, friends and loved ones was acknowledged by all the women.

They type of support provided and solicited was different for every participant. Some women wanted emotional support while others wanted people to attend doctor's appointments with them. Some people measured support by contact and the ability to trust.

His dad, you know what I mean, um, I mean, he supports me, yes. But do he bring me down too? Yes. So can I could you as my support system, no. I need you to support me nonstop no matter what the situation is. I don't need you to support me here and then not support me at this situation. So no, I don't have a support 'son, I have no one but my son. I don't talk to family. I have three friends, my best friend, and then my girlfriends I call my little sister...Especially with my health, with depression, with anxiety. Just with everything I'm going through, I just need the support system. But I feel like once I got my children, I'm okay (Angel).

Just my mom. Yeah. She's, like, my everything. Well, she ... Well, actually she was the one on oxygen now, but she used to come here. She used to come here to all the appointments. She used to come to just before they moved beyond here, she used to come to here, too. But when they moved down here, but when they went across the street upstairs on the third floor, she would come there. She would go to [Site}. She would go to [Site]. Even when I was in the hospital with my ulcerative colitis, I stayed a whole month. She was there every single day (Cheryl).

Joy reflected on the relationship she had with her deceased adoptive mother, "She was amazing...when she found out what I had [HIV], she just like "I don't care. Imma still take her. That's, that's going to be my daughter" and she raised me as hers."

My support system, um ... I have a pretty good support system. Um, I have my mom, I have my sisters, um, I have a-a she's my god sister, like we're really close, and I feel like, um, if it was, uh, to come to a point where I would need them, they would be there by my side (Lilly).

My husband, he's- he's overly supportive. Like, annoyingly supportive...Like smothering sometimes. He's like that. But, um- Whatever. School. Working. If I wanna stay home, he, um, the kids, make dinner, with some things I deal with, um...with, um...I have a hard time since I was, um...like, dealing with my children because I have things going on with me, um, because of my upbringing, um, yeah. So, he's...he's the emotional parent. Put it like that. I'm like the enforcer and the- he's the emotional parent, and I'm glad it balanced out like that, because I was not able to be like that. Because of my upbringing and my experiences in foster homes and things like that. So, they have the sensitive parent, which is him (Marie).

The ways in which support was offered by family and loved ones to the women was demonstrated in the women who reported as having good health and wanting to stay in control of their HIV.

So now, that it's just me and my siblings because I lost my mom two years ago of cancer, it's like, my siblings, like they joined in a little more because "Oh, my sister's sick, you know, she beat cancer, but she still got HIV and she gets sick a lot."So we're a little closer. They're like really tight, and they ... They're there every day and take me me to the clinic or my nurse, but they're all here for. Like, you know, they just come visit, like you know. So I have a hell of a support team, and then I have my kids that loves me to death, my crazy husband (Markel).

My support system is not there, not great at all. It is just my kids' father. That's it. Um, with family-wise, the way family is, like, I think they will cut me off completely, because the way I hear 'em talk about other people- um, mother always been there through the good and the bad, so my mother, so I call her like for advice, she's always there for me. And she's just so loving, so caring, so genuine, so real. She's not fake (Rahvens).

Coming to my appointments with me, making sure I'm okay instead of just asking when I come home and be like, "Well, how was your appointment?" No, if you want to know how my appointment, you should have been there. Um, um, making sure I'm okay. Check up on me. Make sure I'm not, you know, drowning in depression or, you know, thinking about suicide, or whatever (Shana).

### *Stigma*

Many of the women reported having a support system and equally several women experienced stigma. Stigma was reported from multiple areas in the participant's life, predominately family and partners. Women in the study described experiences where they faced stigma and discrimination. HIV-related stigma was expressed throughout the interview as was personal rejection, direct and indirect from family and friends. Rahvens and Sade both mentioned in their experience that they do not solicit help from public programs despite being qualified for aid due to the diagnosis because of stigmatization. The women in this study lived through various life challenges both traumatic and others related to daily stress. Some of the women were born with HIV, while others were infected at the age of fourteen years another at the age of thirty-seven; understanding factors such as some of the negative experiences shared surrounding stigma provides insight into the ability for the women in this study to be supported and successful with the adherence to treatment, risk behavior, and overall wellness.

It is not like I'm afraid of telling the world that I have HIV, it's just not everybody's willing to accept that, and they will look at you like, "Oh my gosh. Get away from her. Duh, duh, duh, duh (Shana)

Because, if I was trying to get a boyfriend, or, or just a friend, that I just had sex with, he is, if I told him I have HIV, he'll be like, "I don't want to talk to you," because I got HIV. So it is like, to some mans a turn-off, and yeah, yeah, now I'm going to have sex with [inaudible 00:19:41] got HIV. They don't want to get it (Shay).

Women reported that when they heard friends, people or witnessed stigma surrounding HIV, they often went underground and committed to themselves that they would “never” share their status to that person or in that environment. Cheryl reports on stigma that occurred at her church where a woman was not supported and experienced humiliation after her courageous act of sharing her story:

Like for instance, lady at my church. She doesn't go there anymore, but she went there for like probably 50, 60 years. But she probably was HIV positive probably for 30 years. Her husband gave it to her. She said that he was in a, he was transition. When he went out and got high he dressed up and, you know, he did all kinds of things for drugs. And I guess her mother passing away ... Her mother had died and I guess she felt like she just wanted to share. So she just got up on the podium and that was one of the things that she shared. And then after that it was like people didn't wanna hug her. They didn't ... it was like just, you know, they was different towards her and I guess she felt it. Like she stayed there for maybe months and months and then after that she left. And it was the church that she grew up at. But it just was like ... not everybody. You know, but it just was few that you can see was like, "Oh, man. They got ... " You know, the whispers and the, "I'm not hugging her." You know, 'cause you know when church people might kiss you on the cheek or something like that. So it was more so like, "I don't want her touching me," or, you know (Cheryl).

As a result, from this interaction, Cheryl stated she will not share her status at any church. Stigma from family can lead to isolation and disconnection from loved ones. It also undermines the desire for connection and safety among the women that shared their expectations of the people that support them. Hope provides an example of her community's view of HIV, while Markel discusses part of her family:

Or it's the stigma, the stigma I don't like is, you know, I don't like the ill stigma. Like people think of somebody with HIV just like, "Ew." And then you, you think about somebody with cancer, and it's like, "Aww," you know? It's sympathy (Hope).

Yeah, the bougie family. You know, you always get that bougie side, but I don't deal with them anyways because they don't know my business anyway. The way I hear 'em talk about other people, that's how I feel like they- they gonna cut me off (Markel).

When you hear people talk, everybody be like, " don't wanna be HIV positive." Like I mean I don't sit around other people and just ... I just listen to people conversations. I think that's why a thing with me never telling people or certain people that I have HIV 'cause I just listen to the way people talk about people with HIV (Cheryl).

Rahvens describes her family's lack of education surrounding HIV and their responses to another family member that was living with HIV.

Like, years ago we found out that a family member had it and I was going ... I had kids around this time and I was gonna watch her kids because she had a situation with housing. And I was gonna watch her kids. They was talking, "No, don't- don't watch her kids. I don't want you to watch her kids, because she has HIV and you don't know if their kids do," you know, and I felt some type of way, "Why, like, why do y'all feel like that? (Rahvens).

Social media offers a newer platform for misinformation to spread and be linked to people that are living with HIV.

And because why, is because the world, we, it's so cruel out here that people that put their personal business, somebody just exposed somebody on social media about this HIV stuff. Took a picture of their medicine bottles, they name. Picture of them. And put it on social media so that's why I say, I don't, I don't talk to nobody about my status, you know what I mean? It's just, it's just that. Like I just, it's just so many cruel people out here that you can't trust no one (Angel).

He [person who infected Marie] was recently, um, he recently gave it to somebody else. I'm thinking it's, it's like seven women total he gave it to. Um, and one of the girl's family members exposed him on this page like, "Watch out for him." Put his picture and all that. Me and her are on the phone, and I'm like, "Wow, you know, it's about time (Marie).

The ability to share with others one's status and still be safe among the support system, not ridiculed because of stigma or past experience creates a safe place for women in this study. When women felt they were not able to freely share their status they also

revisited areas where they had to cope and face shame and despair. The diagram (Figure 5) explains the major paired theme of outcomes of sharing status with confidentiality and a selection of the primary and secondary themes, stigma, support system and HIV disclosure.

### Theme 3: Sense of Protection

For most of the mothers having a positive status was a surprise; two of the women were born with HIV. Once the women were diagnosed, especially during pregnancy, all expressed what was categorized into two themes, the desire to use contraception before or after their pregnancy and the desire to not infect their partner. Women provided great details about both. See Appendix A – Table 9. Theme 3: Sense of Protection Coding Table for a full list of codes within the category and subcategories.

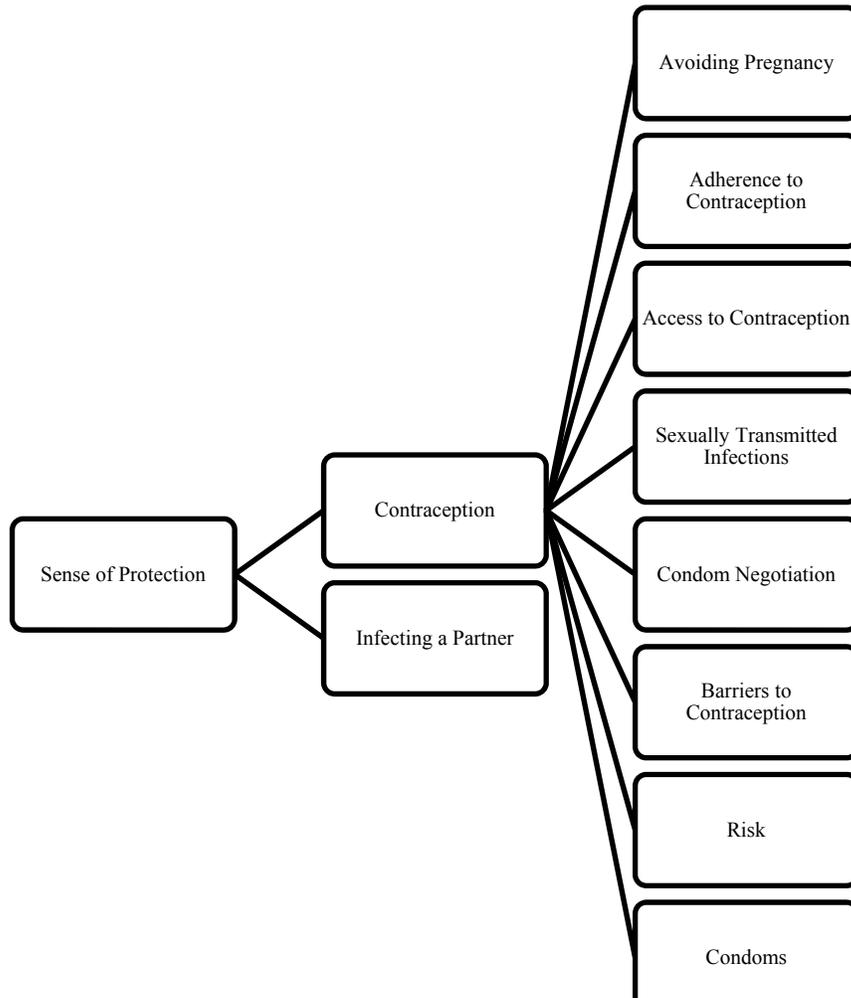


Figure 6: The following diagram illustrates the primary theme, sense of protection, and the secondary themes that are separate which are contraception and infecting a partner.

### *Infecting a Partner*

All of the women took on the responsibility of protecting their negative partner from HIV. It involved discussion about PrEP and the shame and guilt they would feel in the event they infected someone. Protecting a partner was the women's effort to maintain their personal integrity and values for another human being. However, it also reinforced that even if they accepted their own status, HIV can be and should be avoided. Hope described "giving someone HIV as hurtful" and as if it is a purposeful act.

I think that it's a bad thing to do [to infect someone with HIV]. It's like, to me it's like killing somebody else. I don't know. I don't know. That's how I feel. It's like killing someone else. I mean even if you put someone at risk for it or even if you, uh, gave it to someone else. It's just like ... I don't know. It's like ... I'm not saying a person gonna die (Cheryl).

It's medicine out for them now [negative partners] ...Just to keep him safe mostly. You don't want to give him what you got. That's just like it'll stress you out even more, but just like to keep your loved ones safe. Imma talk to him about it. [PrEP] He better be open (Joy).

Um, I think it would be, it would be devastating for me. Um, I've asked him to leave. You know, we've been married a long time. Like I asked him to leave. Like, you know, because, 'cause, and I think it's, it's part him, so he's not, he thinks it's like, because it's been so long he hasn't got it, he kind of thinks like it's not possible at this point. And I'm just like, "Yeah, that's not true." And, um, I just don't think I would be able to live with it, you know? Or I wouldn't want to live it. So every time we come here, I'm just like panicking every time we're waiting for the test results and stuff like that. Um, that's, that's, um, that's not something you want to go through (Marie).

'Cause I don't wanna um, I don't wanna infect nobody. I don't want nobody to be like, "Oh wow you gave me this, you gave me ..." That's my biggest fear. For somebody to come, and they tell people I gave them something and that's a bitterness. I don't want that shame on me. I don't want that, that, their blood on my hands. I don't want that. Like I already got a lot of problems, I don't need that (Sade).

Feelings of protecting the partner were apparent for the majority of women. It also included protecting the partner by insisting on testing. A minority of the women

discussed testing with their partners. Shana continued to have unprotected sex with her partner after she found out about his diagnosis. She shared that she consistently got tested until the day came where her test came back positive. Joy's reflection of testing with her partner is shared:

Yeah, I can tell him to get tested then he gets tested. He's clean. It gives a big lift off my shoulders knowing I aint give him nothing. It's just like a big lift off of my shoulders. He goes to the doctors every three months, so I be chilling with that. So he gets tested all the three months for everything (Joy).

Um, the most difficult part for me has been being in a relationship and fearing that he might it. But he's on a pill, too, to protect himself. So, um, he, he get tested every six months. Um, we come here (Marie).

Well, I use it [protection] because of the safety of the person I'm with. That's first of all, and I'm HIV positive. Who wouldn't want to use protection? Like we're going to, is married, or whatever, who wouldn't want because I dk what you be doing. Well, I use it [protection] because of the safety of the person I'm with. That's first of all, and I'm HIV positive. Who wouldn't want to use protection? Like we're going to, is married, or whatever, who wouldn't want because I dk what you be doing (Markel).

Some women reflected on the possibility that they could have infected a sexual partner.

I have throughout, um ... 'Cause there's people that, when I was younger, um, you know, having sex, and they didn't know, and then you know condoms weren't in use, and that did go through my mind, um ... If they had it [HIV] or not, or if I gave it to them or not. Um ... I mean, nobody told me any- But, just because nobody won't- Didn't tell me anything doesn't mean, you know, that they did get it or not, but, um, um ...(Lilly).

Others found peace in if they shared their status and the person still did not want to use condoms, then the consequence of infection was on them. Women did not question the status of the person who was willing to engage in unprotected sex with them after learning about their status.

Like I say, um, with my past sexual experience, the person knew, so they knew the, um ... They knew the consequences. They were okay with not using, you know, protection, and, um, so I mean, they knew about it, so it was their decision if ...(Lilly).

You found out my status and you're still negative. You know, the odds of 50/50 you can catch it. Kind of. So it's like, do you care, do you don't care, you know what I mean? Do you, stuff like that. So it's just, you know, you know the odds of it. It's just you got to take that caution. You got to take that next step. Now, I told you I'm positive, now it's up to you. You still, you you want to be with me and that is okay. I respect if you don't (Angel).

Shay provided insight into her decision to not use a condom with a recent partner:

Shay: Um, well, one of my friends, he didn't want, he didn't like the way how condoms felt, but I do.

Interviewer: Okay.

Shay: So we didn't use one, but-

Interviewer: You didn't use one?

Shay: No, no, he didn't want it...I had sex without a condom before, but, he didn't, I want, I preferred him to use it, because I told him my status, whatever-Uh, I was like, um, I was like, uh, I guess he just, like, um, I guess he just ... like, um, I don't care, probably or, he'll, he, or if he do care, like, I guess he like, he going to help his own self out

Interviewer: Okay, so you used the words, "that was on him".

Interviewer: What does that mean?

Shay: Like, like, um, it wasn't like I didn't tell him.

Interviewer: When that happens, do you ever question maybe the person's status? Or do you talk about that person's status?

Lilly: Actually, no. It didn't come through my mind. Um ... They did come here to get tested before, and it was negative, so, um, but that is a good question. I never thought about, you know, maybe their status.

Someone thought they was better than me, "Oh well you got HIV, I don't need to be with you, I'm putting myself at risk." I'm like, "Go ahead and leave." And [he] told neighbors to hurt me, but I broke up with him, and he told my girlfriends [about my status], and it hurt, but I'm like oh well ... And when people come to me like well, he must got it too, because the person I was in a relationship with, he didn't wanna use condoms. And I gotta tell him, I'm telling you I have HIV, you don't wanna use condoms? So it was his choice. I gave him a choice (Sade).

Sade: He was negative, but he kept getting these boils. When I met him, he had boils on his- big boil on his forehead and all that, so, but down the line when I was bringing it up, he went to check up and the doctors, and I see in the paper to see, like discharge, why he keep getting them boils and all that so I'm HIV, so I said HIV thing, and I was like, oh you positive, but you're able to tell me your positive. Then he was taking my medicine, my HIV medicine.

Interviewer: How do you know he was taking your medicine?

Sade: Because he asked me, can he take my medicine. And I told him no.

### *Contraception*

When exploring how women prevent pregnancy and avoid the transmission of sexually transmitted infections, responses were dissimilar from the personal shame associated with the possibility of infecting a partner with HIV. Examples were women would not discuss their partner's status, awareness of their status or disclosure when discussing how pregnancy or pregnancy scares occurred. Several did not make mention to circumstances that occurred that lead to lack of contraception. Several of the participants shared they believed the women should make the decision surrounding birth control. Marie shared:

Because, um, they don't have male contraception (laughs). I've seen that they're coming out with that, and I think they should've been did that, um, yeah. I don't- yeah. I think they should've been had that. But for now, because we are the ones that can get pregnant - we're the ones that have to carry the babies - then, um, we should be more proactive than men. They don't fill- they don't have to carry the babies, you know (Marie).

Several of the women reported long-term use of contraceptives. Markel shared, "I don't have my tubes tied. I don't take birth controls. I'm still married and I aint had no kids in 13 years, and we just live our life as it is." Joy explained, "I used condoms and birth control my whole life mostly." Shay explained a recent experience during her interview.

But since I had sex yesterday, uh, and I had got a pregnancy test, the doctor, um, the doctor said she wanted, um, put me on ... She asked me if I wanted to get on, um, any birth control pills. I told her just get me on, put

me on it. She said I don't want to put you on any kind of birth control, uh, things. And I said, pills (Shay).

Most women reported complications with hormonal birth control as the reason they were not adherent to the method they chose, or it did not work. The participants shared they use condoms, while several women use a hormonal method, primarily the Depo-Provera shot followed by birth control pills.

Just condoms. Yeah. Birth control, I mean, that just mess you up all the way. In it, like, your period, it'll mess up your period and all that. It'll mess up your cycle. I mean, you'll ... I used to have my period for five days. Now, I'm having it seven days, eight days. Then I have in-between periods, like, that messed me up a whole lot (Rahvens).

Well, I actually cut it short. I'm, like, um, I don't know ... The last time, I wish I was using 'em. I've used, um, the pills. I didn't like that. I used the patch. That actually had gave me bruising. Um, and then I was using Depo, and that stopped my period. I think that's what made my period stop (Rahvens).

But I was on birth control. If you don't use birth control like you supposed to, your period, it- it ... I don't know if it happen to everybody, but I know when if I didn't take it at the right time each day, sometimes I would bleed or sometimes I would have cramping. Like with the birth control it wasn't pretty, it wasn't pretty good for me. Birth control pills. They didn't work for me so then that's what made me start using the Depo. And then along with using condoms. It was probably like the only two things I use and I been trying to get the IUD for the longest (Cheryl).

Joy expressed disbelief in the effectiveness of hormonal birth control, “Uh birth control will work. Sometimes it don't 'cause my little cousin got pregnant twice on, on birth control with her kids so I don't believe it could work or not work.” Hope shared, “I get Depo because I don't like the cramps.” Weight gain was noted as the largest barrier to success and adherence to hormonal birth control. Lilly mentioned, “Some challenges for me, that I experience with birth control, um, gain weight. I had, in the past, I had Depo. Um, a long time ago, and, um, I really gained a lot from that.” This was also expressed by Marie, “But, um ... I also was not taking birth control either because of I was scared of

the symptoms and gaining weight” and Shay, “I was on Depo shot, I got off of that because I was gaining weight.”

Condom use was the largest reference to avoiding pregnancy, sexually transmitted diseases and reinfection of HIV. The majority of women did not make reference to monogamous relationships but did share they do not negotiate with condom use, the person has to use one. Shana who was infected by a partner she knew was HIV-positive shared, “In my whole entire relationship with him, we only used a condom once and that was the first time we had sex.” Respondents provided details of their experiences.

So the one is not really about the pregnancies. It's really about the STDs, really. That's for the condoms 'cause the birth control can't stop STDs. Well, I'm gonna use condoms 'cause like I was just saying, I don't know if you gonna get infected over and over again. So that's like a worry in the back of my head. And then I don't trust birth control at all no more (Cheryl).

If I don't feel comfortable enough to not use it, um, at that moment 'cause, you know, things do heat up, and sometimes people just it's in the moment, it happens, but me, if I don't feel comfortable enough to, I would not do anything if the person doesn't have a condom (Lilly).

I know condoms aren't 100%, but that can be another thing. If you don't use them, and a lot of people think, um, the pull-out method is a ... Women can get pregnant. And, um, you know, with the condom breaking, or popping, um ... You know, while you're having sex, it comes off (Hope).

And use a condom, even if you using a condom sometimes they kind of break, but make sure you ... make sure you're good and make sure he pulls out before he starts to say, "No, no, let me go even farther," you know. Make sure you're um, if your partner has that, please don't wait until you have sex or wait till y'all, you know, level-headed. I'm not saying just shout out like, "Oh, I have HIV." No. Be comfortable enough, uh be comfortable enough and be confident enough to tell your partner that you got it. And if the partner wants to stay with you, I advise you to use condoms (Shana).

Some of the women in the study adapted a “no condom, no sex” approach to protecting themselves from pregnancy and sexually transmitted infections. Other women used condom negotiation skills to express their desire to use condoms and their concern with not using them. Women did not mention gender, power or control imbalances that could impede on the success of her condom negotiation ability. Women shared their obstacles to condom use:

Um ... Sometimes the guys will try to, you know, "Oh, it's gonna be okay. I do- You don't need it." And then, I just feel like it's not only one person's decision. It's ... You know, you two together talk about it, and if y'all decide not to use it, then that's y'all decision (Lilly).

In the future? I'd just say we will ... Th- This ... I'm gonna be ... Well I'm gonna honest with the ... with ... We're gonna have sex. We ... This is what we gotta do... We gonna go to the store, we're gonna get a box of condoms (laughs) (Sharon).

Other women mentioned various obstacles to condom use. “Uh, my greatest challenge has been sometimes people say they don't have condoms” (Cheryl). Shana reflected on her relationship and shared, “Oh, he always would say it don't fit, it's too small, um I don't have any. So he was just always just making excuse about not wanting to use a condom”, while Hope made a generalization that, “Guys don't like to use the condoms.” Sharon provided insight into when she decided not to use a condom and she later tested positive for HIV.

None of what ... I ... I would use protection no matter what. Now and I'm gonna use protection no, no matter what. See, I always use it. I always use the condom. I didn't wanna use no condom with at first, 'cause, uh, that was my boyfriend, like I'm ... we was going for a while. For a long ass ... uh, for a long time. So ... But anybody else, I use condoms. I d-, I'd ... I protect myself well, I just didn't protect myself this time (Sharon).

Other obstacles to successful contraception use include missing follow-up appointments for contraception and condoms breaking: Cheryl shared, “depo, but then I missed it like here, in between, so I'm like, wow.” Sade missed four depo shots, “I was on Depo, but I got off Depo. I missed like four shots, and I got pregnant.” Hope shared it is very clear that not using condoms can lead to pregnancy, “Hey ... Having sex you never know if you going pop up preg-, pregnant if you not using condoms.”

Every woman agrees that contraception, condoms and birth control, are easy to obtain. Several referenced the clinic provides free condoms in a brown bag. More than half of the women had a no tolerance for not using condoms.

I mean if you go to the clinic you can ... if you go to a free clinic, they give 'em [condoms] out free. You just going in, say you need protection. They'll just give you a bag. You know, they not gonna ask too many questions. They'll give you a bag now and you can go to a ... I done seen some places, Chinese stores got 'em hanging up in the- the- the front view. Like, which is crazy, but just saying like now you could just (laughs) go anywhere and buy a condom (Cheryl).

Two women mentioned they both had gonorrhea in the past, while a majority of women stated they never had a sexually transmitted infection or made no mention of their history.

Interviewer: What are your thoughts about other sexually transmitted infections or diseases?

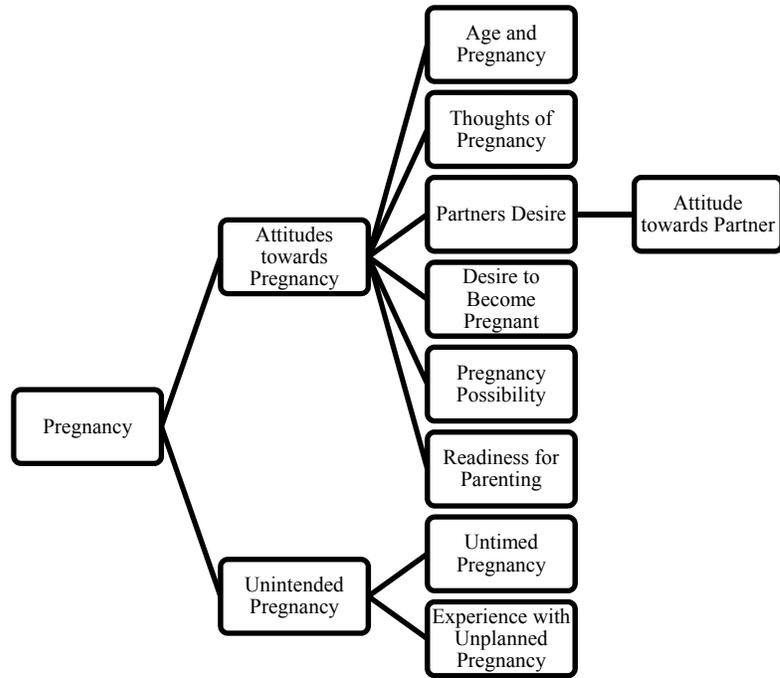
Cheryl: So some people, I don't think some people be realizing like, "I'm on birth control," but they still don't use protection. So that's really one of the big issues. I think it needs to be more people talking about not just using the birth control just for that so you can't get pregnant. That you need to be using the birth control, yeah, so you can't get pregnant, but also you need to be using condoms. Like some people like, "Oh, I got the IUD," and then whatever the other thing is. What is that, the Urana or something like that is that called? Something that goes in your arm and it's something that's. But just saying, it should be implemented more that it's just not about getting pregnant. 'Cause they mainly talk about pregnancy, about using protection so you can prevent being pregnant. But they need

to say so you could prevent the STDs and getting HIV because that's really the main factor is really.

The need to be loved or maintain a relationship because of power or financial support was not explored and discussed by the participants. However, the ability and skills to make decisions about contraception and the commitment to not infecting a sexual partner were overestimated. Women in this study drew on their experiences and saw how they play a role in deciding for themselves and at times their partner through boundaries. The following diagram (Figure 6) illustrates the major paired theme of sense of protection and two primary themes, contraception and infecting a partner.

#### Theme 4: Pregnancy

A number of women reported pregnancy after their HIV diagnosis and when they received a positive result. Pregnancy and thoughts of pregnancy were optimistic for the women. Despite their initial feelings of despair when they were diagnosed with HIV, many of the participants were optimistic and hopeful that HIV does not mean you can't have children. In some instances, pregnancy empowered women and increased their desire to cope with living with HIV. Women provided insight into their attitude towards pregnancy and factors that greatly influenced unintended pregnancy. Overwhelmingly, women found comfort that they were able to have a child that had a decreased chance of HIV transmission. See Appendix A – Table 10. Theme 4: Pregnancy Coding Table for a full list of codes within the category and subcategories.



### *Attitudes towards Pregnancy*

Maternal age of a woman was mentioned by several participants. The women who were nearing forty in age shared that their provider suggested they think about pregnancy before 40. Cheryl and Sade provided insight to her thoughts about age and pregnancy:

I will be 40 this month. So, I was actually 38 - no, 37 turning 38. So, it was kind of hard [my pregnancy]...sometimes they say, with age you have, like, with the- you gotta be careful with the diabetes, you gotta be careful with the blood pressure, and then it depends on your body, like whatever your body's really going through far as with age, cause sometimes some people can be 40 and be healthy. Some people can be 30 something and healthy. And then I have friends that was actually younger and got diabetes while they were pregnant, and still have diabetes. So it's like- it's just like, it depends. They just say you have more high risk after a certain age (Cheryl).

And then like, I went and talked to my doctor too, and she's like, Yeah, 'cause you're still young, but you wanna you know, have a baby before you get 40 because you don't make eggs like you used to when you were young, you're not as fertilized like you was when you was younger, so if you're gonna do it, do it now, don't wait till you're 40. You're 31, so you gotta do it now (Sade).

Joy and Lilly are both in their early twenties. Their responses to age and pregnancy were quite different. Joy shared, "I'm not in no rush. I'm still young", despite stating she wants to try having a baby soon and "If it happens, it happens. All I know I better have them before I'm 30 'cause I don't want no kids after I'm 30". Lilly also mentioned age and stated, "I feel like that's a good age to, I'll be like 25, 26. I feel like that's a good age to start, you know, thinking about it, at least. Most of the participants all stated they have thought about pregnancy. These thoughts were considered with age, fit of the parent, having a pregnancy scare and before confirming thinking about the possibility, partner and wanting to conceive but due to birth control and natural causes a pregnancy did not occur. The desire to become pregnant was entrenched in the desire to love and care for someone of your own. Angel shared,

Let me have my own babies. Can't nobody take mine's away. And I did. I ended up having my own and I had a baby shower. My brother threw me a surprise baby shower and I just was, like, ready for the nine months. My nine months felt like it took forever (Angel).

This desire was also shared by Joy, "Cause I always, I always wanted a baby like I wanted another life just so I could support them and all that, just show them somebody I could love and all that. I just want somebody else" (Joy).

Sade agreed that some women may want their own child for their own needs of love and affection, she shared:

Cause they want somebody to like ... They want a- a pers- well they want a little baby to care for and love, and just have, and they're present, and um, comfort 'em, and just why they want to comfort a baby, and they just want the baby to be there beside them, so they can do stuff with their child. And someone they- they could care for, make them feel so important. (Sade).

In their own childhoods, both Joy and Angel did not have a connection with their maternal mother. Joy was adopted as an infant. While she was introduced to her maternal mother and had opportunities to interact with her, she preferred to stay distant. Angel shared she does not speak to her mother at all and that she stays away from her.

Some women mentioned they have had thoughts about and possibilities of pregnancy. Lilly was able to provide a timeline to her wanting to become pregnant, but did not define her thoughts as planning, "I haven't thought about getting pregnant, um, in the past or now, but I do plan on maybe in about a year or two, um, to become, to start becoming pregnant." Lilly and Sharon acknowledged that they both were not on birth control and that a pregnancy could be very possible, while Markel is also not on birth control and shared becoming pregnant is not a possibility.

Most women reported feeling happy or shocked when or if they discovered that they were pregnant with a few women reporting negative feelings that they would be unhappy or mad because of the timing or not being prepared. There were several women that based their attitudes towards pregnancy on their partner's desire to have a child. Angel's second pregnancy was planned and discussed with her partner who had no children and desired to have one. She shared "I got pregnant with him ... His daddy planned him" (Angel). Rahvens second child was agreed upon mutually when her husband stated he wanted a second child. Marie also shared she planned one of her children based on her husband's desires. She stated:

No, it was, it was like- well we were married- well he already had a lot of kids before we were married. But he wanted a girl, so he thought I would have a girl, cause I already have a girl - which makes no sense, but um, it was a boy. So, that's the way- it wasn't like an agreed upon thing, it was like him throwing it out there, and, and I would just be like, how do you know it's gonna be a girl, you know? But um, I think maybe consciously I wanted to give him a daughter, I guess. But I um- no, it wasn't planned (Marie).

Several of the women mentioned that their boyfriend or partner at the time did want a child, but not at that time. Sade stated, "Well, my baby daddy, he did want kids, but he ain't want it right then and there (Sade).

Readiness to parent was explored among the women. Factors that influenced if a person was ready to parent included age, personal educational goals, finances, relationship with the partner and your lifestyle. Several examples of being pregnant, but not ready to be parent, were provided.

I was in [foster care] from the age of two to twenty-one, and, most of us was - the four oldest - um, were, like, house hopping, and living on the streets, and doing whatever. [My mother] was on drugs, um, my dad was an alcoholic, so, yeah, she was in situations where she could get pregnant, but she had no intentions of being a mother. That's why all of us was in

foster care, and group home, and-runaways. And, the last one was in the foster care for a little bit. And then she got clean, and tried to like do things over, but it was pretty much too late after that (Marie).

They gotta get their hair done right behind me. If I go shopping, go get me some jeans, they gotta go get the pair of jeans too. I can't walk down the street and look better than your child. You can't do that. That's making you look bad. You think you're making you look good, but it's making you look bad. So some mothers out here, I don't respect at all. (Sade).

You can have a baby to keep a man, you could have a baby to get a cheque, you could have a baby to get an increase in food stamps. I've seen it all, you know. Um...there's a big difference to getting pregnant and just being a mother. (Marie)

Each woman had a personal take on living with HIV as it relates to pregnancy.

Women described their experiences different as it related to when they were diagnosed and when pregnancy occurred. Hope went to the doctor complaining about stomach pain.

She described facing pregnancy:

Wow. When I came to the hospital I was coming to the hospital just to get my Depo shot. And I check [inaudible 00:05:52], and I was like, I asked the doctor. They said, take your arm. I want my Depo shot. I was getting my period. And when they [inaudible 00:06:14] they said I was pregnant. I said, I ain't pregnant." I was scared. I was like, how I'm pregnant? I was getting my, I was still getting my period. She was not prepared for her pregnancy or thinking about her HIV status. (Hope).

Marie had one child prior to her diagnosis and several after. She provided insight into differences with having children pre and post her diagnosis.

So believe it or not, it wasn't really a big difference. It was more annoying as far as the doctors because they were, you know, really on you, like, Oh, you have to take these pills, you know, to protect the baby. Um, but that was easy because you know, you don't want this child to have what you have. So it was really easy. Like even ... I-I'm not- I don't take my medicine faithfully like I'm supposed do everyday because I'm forgetful. And they're working on giving me monthly shots so I don't be so forgetful. But when I was pregnant I had to be, um, consistent with my pill-taking because I did not want my sons to come out- I didn't want them to live with that. (Marie).

Both Rahven and Marie mentioned the number of doctors' appointments that needed to be attended due to HIV and pregnancy was the only major difference than a pregnancy where a woman is not positive. Three of the women mentioned delivery modes but provided a medical reason or stated they chose to have a caesarian delivery, not related to HIV status. One person shared you should not breastfeed your child. Markel has nine children, she shared her pregnancy with her children after being diagnosed were the same. Markel was tested very late in her pregnancy; her youngest daughter (age 15) is HIV positive.

Overall, the participants were knowledgeable of HIV infection routes of transmission to an infant. They were aware of successful treatment strategies to prevent mother-to-child transmission of HIV and adequate knowledge of medication complications and possible birth defects. Women shared eating well and staying stress free during pregnancy was important. There were mixed messages about vaginal or caesarian delivery for the mothers and limited discussion of breastfeeding. For the women who experienced pregnancy while living with HIV, none of the women mentioned transmission of HIV to their partner. All of the women were knowledgeable of preventing pregnancy.

#### *Unintended Pregnancy*

For the majority of women in the group pregnancy was often unintended and described as unplanned. Once pregnant most of the women reported having healthy children. Moreover, every woman, when asked to share something about herself defined themselves as a mother. Four of the women did not have children, but all at some point

had to take a pregnancy test to ensure they were not pregnant. Three women reported as having planned their pregnancy. Casual and unprotected sex was the main condition that influenced unintended pregnancy. Many of the women defined unintended pregnancy as not planning to become pregnant; not intentionally becoming pregnant and making reference to “it [pregnancy] just happened” (Joy) or you “find out you’re pregnant” (Cheryl). Markel has nine children, she stated, “It wasn't like we was planning on having a baby. It just happened. I've got nine of them, and I aint plan all of them”. Sade related both casual sex and pregnancy, she stated, “Kinda have sex and get pregnant”.

One participant did not support the idea that pregnancy just happens. Marie shared that people just don't get pregnant and that pregnancy should be avoided. She did offer leniency to this by stating,

...if in the midst of taking birth control, or getting the implants, or whatever method you wanna use, then you get pregnant - then okay, you can say, I didn't want this to happen, but it happened. Then it's a mistake. But anything besides that is not (Marie).

While Marie did not support, “You just pop up pregnant”, she believes most pregnancies do not follow a guide and that most people that experience pregnancy do so unintended and this is the norm.

Women used the term unintended interchangeably with unplanned and untimed. However, all the terms were conceptualized differently by the participants. Unplanned pregnancies were associated with the outcome of the sexual experience was not supposed to be pregnancy. Untimed stood alone in that it allowed the women to think about life events that were occurring during the time in which the pregnancy occurred. Unplanned was not associated with a choice to abort or continue with a pregnancy, whereas untimed

the belief of moving forward or terminating a pregnancy was weighed in the context of the circumstances of the mother and at times the father. Marie discussing the circumstances surrounding her pregnancy when she tried to enroll and continue with school.

Cause I was, um ... I just had signed up for school and I was goin' hard in school and I, um ... The school I was at, that time- No, that was after. Um ... No, I just started school and I- That was my ... I wanted that to be my priority after ... after, you know, I was like, "Okay, he's getting older," and, you know, I think he was about two. He was walking and I had him in daycare and, um, I was like, "Okay." You know, and ... Then bam. I'm pregnant again and it slowed me down again (Marie).

“Mmm. Untimed pregnancy was ... In this thing my, um, the timing was wrong and so much is going on at this time, you know, and I don't know (laughs) yeah.” (Markel).

Markel discusses that competing priorities were occurring the same time a pregnancy was confirmed. Rahvens describes the same idea that a “lot is going on” but introduces the idea that all things do not have to be negative, “Right, anything- anything could be going on, like, and that's going on in your life, like, uh, it could be a lot- lot of things that's, um ... Let me see, um, lot of good things that's going on”.

Well to me it's like ... I'mma tell you like, like me with my other three kids that I have, like they was untimed, because I wasn't ready. Um, I wasn't prepared. Like it was like, um, I wasn't working. And then had just splitted apart. So it was like I was just in all by myself for a minute (Sharon).

A major difference in planning and not planning a pregnancy is the verbalized option of ending or continuing a pregnancy. This option is not there with a pregnancy that is planned. Sharon states, “No, 'cause I had an option... I keep it, I get rid of it. I- in my heart, I don't believe in that stuff. Markel offered a black or white approach of making a decision as it relates to untimed pregnancies, “I-I that's-that's-that's ... It would to me. It's not no un-timed pregnancy, like it's just you pregnant. You can deal with it or you don't

deal with it. It is what it is". The news of pregnancy was shocking for some of the women that experienced unplanned pregnancies.

I went to St Joseph for a complaint of stomach pain, because I had ulcerative colitis, and she examined me, and then she of course said obviously you're pregnant, he said to me, he said like, you have pain, cause they figured maybe it's like IBS, some type of disease, on and on, or whatever the case may be. So then she left out the room, how the hell, oh, she was like, "I gotta get the ultrasound machine". I thought, okay, my stomach really must be jacked up. So then she comes back and she was like, "Well I just wanna tell you that you're pregnant." I'm like, "Huh?" Like, that's the last thing that would of even come possible to my mind, because I was using protection every time (Cheryl).

Hope experienced an announcement of pregnancy at a scheduled appointment for birth control. "With my son, because I was getting my period, and I came here to get my Depo shot. (laughter) I was two months pregnant. He (laughs) pop up out of nowhere" (Hope). Marie was the only women who stated she did not want children. However, she has three children, she states, "None of my pregnancies were planned. Um, they were all unintended. I never wanted any kids. I just decided I didn't want no kids at- when I was 13. (laughs) I still don't know how I have three kids (Marie).

In recounting their experiences, women described the dimensions of pregnancy occurrence candidly. Marie describes her pregnancy occurrence, "I was a 15-year-old girl, and I didn't have no adult supervision. I shouldn't have got pregnant at 15". Shay describes a spontaneous approach to discussing pregnancy while Rahvens contributes her pregnancy occurrence to alcohol:

"Like, uh, they have, uh, sex with somebody and the guy just asks her, do, do she want to have a baby, she just says yeah, so, they just decide to do it right. It wasn't planned out. Uh, well, they was having sex without a condom. And the guy just her and then she just got pregnant" (Shay).

“I actually didn't think about, you know ... (laughs) ... getting pregnant again. It was just, you know, it was one day where me and my kids' father was- was drinking and that leads up to me getting pregnant again” (Rahvens).

Cheryl discusses the possibility that two partners may not be in agreement with the final decision of having a child:

“Like, some people go their separate ways. Like, you have people that get pregnant, they might tell the person, "Well I don't want the baby." You know, then the person might want the baby. Or the other person - the male might want it, and the female might not want it” (Cheryl).

During the interview, women discussed their thoughts and experience surrounding pregnancy, contraceptive failure and misuse, as well as their readiness for pregnancy.

The participants talked about where they were in their lives when they were faced with heavy decisions surrounding pregnancy. They spoke of factors that influenced the meaning of unintended pregnancy for them and talked about issues affected by their HIV.

The fourth theme Pregnancy captures the participants attitudes toward pregnancy and their attitude surrounding pregnancy as well as their experience and definition of an unintended pregnancy. Figure 7 depicts the conceptual categories as well as primary and one secondary theme.

## Conceptual Model

The proposed theoretical model explains unintended pregnancy using grounded theory. Grounded theory provided an ideal framework to identify key categories related to African American women living with HIV experience surrounding unintended pregnancy. The final research question was to identify and describe unintended pregnancy by developing a theory that emerged from the group of women. As applied to unintended pregnancy, the proposed theory posits that women are most likely to have an unplanned pregnancy if: 1) they have a poor attitude and outlook about pregnancy, and if 2) they are less likely to protect themselves or their partner from infection by use of contraception, 3) are less likely to share their status and disclose, and 4) exhibit poor coping. Other selected components of this model are perception of fear, mental state, medication adherence, specific types of disclose (who the woman discloses to), access to contraception and partner's desire. These variables all affect the major themes.

Resilience is the ability for a person to cope and overcome challenging life events, it strengthens and reinforces culture (beliefs and values that nurture empower and encourage), living with HIV (the intrinsic desire to live well) and pregnancy outcomes (the ability to overcome stressors related to fear, negative responses and plan outcomes). Resilience is influenced by and can influence outcomes of sharing one's status which is in direct relationship to stigma, that is related to the women's support system and the ability to disclose her status. Outcomes of sharing one's status is influenced bidirectionally by sense of protection. Women have a sense of protecting themselves from the risk of pregnancy and sexually transmitted infections (contraception), which having this sense of protection is related to the women's stance on infecting a partner

with HIV. The perceptions a woman has about contraception can lead to barriers to contraception or contraception failure. Sense of protection is the only concept that leads to pregnancy, which also fosters attitudes towards pregnancy and can lead to an unintended pregnancy. Additionally, unintended pregnancy is influenced by pregnancy outcomes (the ability to overcome stressors related to fear, negative responses and plan outcomes), the support the women perceives she has, the ability to disclose in safety her status which can weaken or strengthen barriers to contraception and again lead to an unintended pregnancy.

This study explored the phenomenon of unintended pregnancy among African American women of childbearing age living with HIV. Figure 8 provides a diagram of the proposed theoretical model.

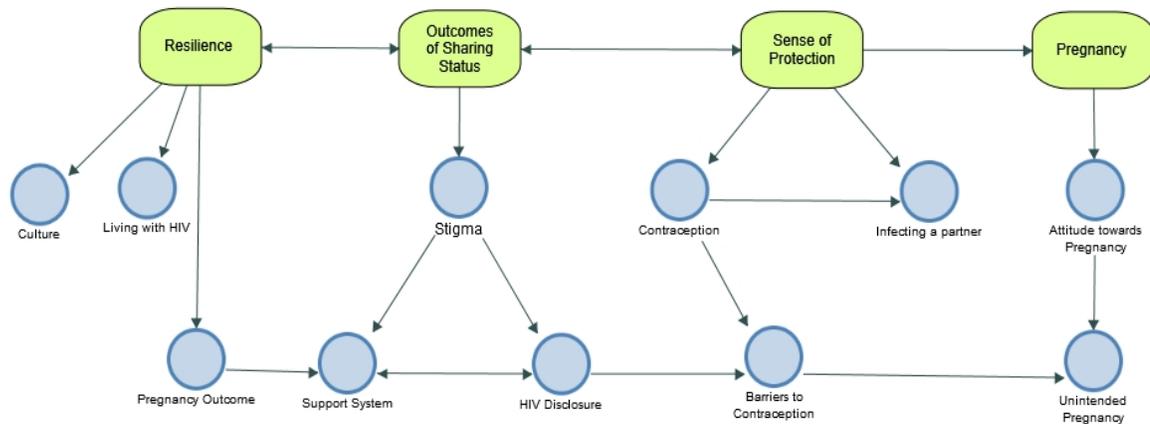


Figure 8: The grounded theory model of the meaning of unplanned pregnancy in urban African American Women with HIV.

### Conclusion

This chapter included the overview of an interactive theory that emerged for understanding unintended pregnancy from the experience of African American women of childbearing age living with HIV. The overall categories supported by primary and

secondary themes were described and verbatim narratives were provided to bring meaning to the participants experiences in their own words. The major themes entailed resilience; outcomes of sharing status; sense of protection and pregnancy. Primary and secondary themes included: culture, living with HIV, pregnancy outcomes, stigma, support system, HIV disclosure, contraception, barriers to contraception, infecting a partner, attitude towards pregnancy and unintended pregnancy. The model proposes that an individual's unintended pregnancy is determined by the congruence between their resilience related to living with HIV, culture and outcomes of sharing her HIV status, use of contraception and infecting a partner and attitudes surrounding pregnancy. For example, a woman who describes herself as coping well with living with HIV, overcomes and/or has few negative experiences with sharing her status attributes a high level of importance to protecting their partner and thoughts about pregnancy. Consequently, the ability for a woman to describe each area as congruent coincides with their underlying values about pregnancy because each can facilitate the outcome of a planned or avoided pregnancy (the ability to be resilient) or unintended pregnancy (lacking resilience). The data also suggests women who described the ability to be resilient also recognized support systems, could disclose their status and overcame barriers to contraception which in turn reported less occurrences of unintended pregnancies among the participants.

The emerged theory addresses specific components of the proposed research including common attitudes and beliefs about the meaning of unintended pregnancy, health care and engaging in the continuum of health care, common beliefs surrounding among African American HIV-positive women and pregnancy and the psychological, social, and contextual factors that are characteristic of African American women living

with HIV who experience an unintended pregnancy. For this study, the participants definition of unintended pregnancy was broad and did not carry a negative connotation. Similar to findings among all African American women, the concept of pregnancy intendedness is complex and may not be defined the same by all women (Solomon et al., 2017) . These findings have implications for research and family planning policy.

## CHAPTER 5: DISCUSSION

### Introduction

This chapter discusses the findings as it relates to the phenomenon of unintended pregnancy among urban seropositive African American women. Drawing from the findings, the emerged theory, the reflexivity of the researcher, the strengths and limitations of the study, and suggestions for further research are discussed. The aim of this research was to explore the personal thoughts and experiences of women who do not have surgical sterilization, were not pregnant at the time of the interview, and can have an unintended pregnancy. Interviews were conducted from a sample of fifteen African American women living with HIV. Using data from the interviews a theoretical model explaining unintended pregnancy was developed. Three women were excluded from the study late in the interview due to their revealing that they had had a surgical sterilization. The findings are based on a sample of twelve women.

#### *The meaning of unintended pregnancy*

Unintended pregnancy is a complex and subjective phenomenon. While the occurrence of unintended pregnancy is rooted in understanding fertility by public health entities, for women it relates to a sexual encounter where pregnancy was not the intended outcome first and the description of the type of pregnancy using terms such as unwanted, unplanned and/or untimed are secondary and associated with acceptance of personal and social conditions, personal scrutiny and readiness to become a mother. Seven participants in the sample experienced an unintended pregnancy, three women experienced a planned pregnancy and four women did not have children and have never been pregnant. The participants in the sample provided different perceptions and clarifications of their own

experience and contextual factors under which unintended pregnancies occurred based on their environment, age and personal characteristics.

Several participants who experienced an unintended pregnancy had no symptoms of pregnancy and no intentions to take a pregnancy test. Participants were aware that they had unprotected sex, however shared they were taking a form of contraception that failed due to adherence or experiencing a health issue that resulted in medical attention where taking a pregnancy test was recommended by the provider. All the women reported they were shocked when given the news of a positive pregnancy test and were several gestational weeks into their pregnancy when they found out their pregnancy test results.. Similarly, participants associated their pregnancy as untimed and unplanned in that they were experiencing financial difficulties, completing a personal goal or already had a child they were caring for. Some women acknowledged their awareness of the risk for pregnancy occurring when not using contraception. Some also pointed out the fallacies of birth control methods. However, some struggled with this view as justification for their awareness of the risk for pregnancy.

Participants reported obtaining information on unintended pregnancies from people they knew, most commonly their parents and siblings. Some reported relying on their personal beliefs on terminating a pregnancy. Participants focused on how they defined unintended pregnancies and examples of timeliness of a pregnancy. Women expressed how motherhood was part of their social identity whereas unplanned pregnancy was viewed as an incident. Participants compared their pregnancy and their becoming a mother to that of people they knew who they described as unfit mothers. Accordingly, unfit mothers were women who left their children, allowed others to raise

them, had children for financial gain, and placed their own happiness above their children's' happiness. Participants who reported that they experienced pregnancy as unintended went through with their pregnancy. None of women who were pregnant said they contemplated terminating their pregnancy.

Several of the participants shared their experienced with contraception failure. Many of those reporting contraception failure shared that they had received a Depo-Provera injection. No one voiced use of condoms to avoid pregnancy. Women who had not experienced an unintended pregnancy or were never pregnant voiced adhering to contraceptives to avoid pregnancy. All discussed using condoms with their sexual partners citing condomless sex would highly result in an unintended pregnancy. There were no differences in reported sexual behavior, pregnancy experience, and intentions to prevent transmission of HIV between women who were perinatally infected and women who reported being exposed to HIV through sexual transmission. This finding is consistent with the literature (Haddad et al., 2018). Participants who were perinatally infected with HIV shared that they had had unprotected sex knowing that they could have become pregnant. Analysis of the data revealed that women who did not know their HIV status prior to a pregnancy appeared to be more likely to experience having a subsequent unplanned pregnancy.

#### *Managing diagnosis*

Women shared how managing a pregnancy diagnosis was complicated by simultaneously receiving an HIV positive diagnosis. Women who had never experienced a pregnancy stated they would be shocked, but happy if they ever experienced an unintended pregnancy. Women who had experienced an unintended pregnancy diagnosis

while simultaneously receiving a positive HIV diagnosis shared their concern about putting their unborn child at risk. Some expressed hopelessness and helplessness as they shared their concerns about perinatal infection. The women did not view their positive serostatus being a barrier to raising a child.

None of the women who experienced an unintended pregnancy elected to terminate the pregnancy. This finding is somewhat conflicting with the literature. A study of twenty-eight seropositive Brazilian women observed that less than half had considered terminating their pregnancy (Maccarthy, Rasanathan, Crawford-Roberts, Dourado, & Gruskin, 2014). Clearly, there is a need to further explore how cultural as well as economic factors including household income and a country's per capita income affect pregnancy decision making among seropositive women (Maccarthy et al., 2014).

Women expressed that their first unintended pregnancies were the hardest to manage psychologically. Several of the women reported experiencing inner turmoil surrounding their dual diagnosis. Some reported trouble in coping when thinking about the possibility of their unborn child being diagnosed with HIV. Some expressed feelings of depression and wanting to harm themselves. Many expressed a sense of being relieved when they learned that their child was seronegative. A secondary analysis of a large cohort study of HIV-infected and -uninfected pregnant women found HIV-infected women had higher rates of depression than women who were uninfected (Angrand, Sperling, Roccobono, Osborne, & Jao, 2018).

#### *Theoretical inferences*

Maternal Attainment Theory emphasizes the process a women experiences during pregnancy as a behavioral transformation in which a pregnant woman self-identifies

changes to that of “mother” (Mercer & Ferketich, 1995). During the anticipatory stage, a woman socially and psychologically adjusts to pregnancy and explores her expectations of the maternal role. During this phase a woman begins to seek information and visualize herself as a mother or not (Mercer, 1981). This phase was gravely disrupted for the women who learned about their HIV status during their pregnancy and for women who knew their status and experienced a pregnancy for the first time. Women in the study did not view themselves as mothers during the transformation phase. Many expressed their initial response to the pregnancy was death and/or no longer wanting to live. For the women experiencing a pregnancy for the first time and for those who were never pregnant and were able to hypothetically play out a pregnancy scenario, all shared they were or would be fearful of their child’s HIV status.

For some women pregnancy served as a source of strength to overcome their sadness and shock by initiating and adhering to their antiretrovirals treatment regimens. Pregnancy was associated with relief for some women who successfully gave birth to a seronegative child. Two women shared how the results of a seropositive birth was associated with personal guilt and shame. Women also shared daunting moments of uncertainty if they forgot to take a pill at a certain time. Other women were relentless and reported no error with the medication during pregnancy because the risk was unbearable. All the women played out negative characterizations of themselves for having a HIV-positive child and undoubtedly reinforcing the complications of being pregnant to becoming mother. Jirapaet (2001) stressed that HIV-positive mother’s maternal role attainment appear to be their determination to live, which is related to the welfare of their child. A significant finding was that women reported higher self-efficacy once they had a

child that was born HIV-negative; they were more resilient and confident that they can have another child. The women were more optimistic and knowledgeable about what to expect.

The role of the father as it relates to empathic tendencies surrounding unplanned pregnancy and learning about HIV status was not discussed. Some women who received their HIV diagnosis during pregnancy did not tell the child's father that they were seropositive until after the child was born. Women shared that after the child was born, they disclosed to the father and recommended that they get tested. Other who shared that upon receiving their diagnosis they emphasized to their seropositive sexual partners the importance of both adhering to their ARV regimens to prevent transmission to a child resulting from an unplanned pregnancy. Discussions on sexual partners and fathering required extensive probing. Many of the women were not forthcoming in discussing the father of their unborn child. Exceptions were discussions on the father with single mothers. These women viewed themselves as the sole person responsible parenting their unborn child. Some women did acknowledge being in a monogamous relationship in discussing the potential adverse consequences from unprotected sex.

### *Stigmas*

HIV-related stigma is associated with depressive episodes, stress and social isolation during pregnancy (Ion, Wagner, Greene, & Loutfy, 2017). This study observed stigma and the influence of stigma on the women's ability to disclose their HIV status. Some of the women described their lack of desire to talk about their pregnancy or be around people because they experienced a different pregnancy than some of the people they were associated with. One woman shared that she was asked why she has so many

medical appointments during her pregnancy. This question caused her to not want to be around people or discuss her pregnancy. Many of the women shared they were afraid to tell their partner that they tested positive for HIV because they thought their partner would no longer want them, they would experience an aggressive response, or their partner would tell others about their status. Women were very protective of their unborn child and living children. Women recognized that negative comments or thoughts that others had about their child based on their status caused inner turmoil and further social isolation. The women were critical and very selective about who they shared their status with, which was dependent on their experience within their culture where people who were diagnosed were talked about previously. For instance, in the families where HIV was not associated with a behavior like drug abuse, sexual orientation or being promiscuous, women were more likely to disclose their status and perceived their social support as good. This was over emphasized by the three women who were perinatally infected. They were critical of people that discussed HIV with high risk groups only; they felt protective of themselves and their status.

Some women reported experiencing how a family member who was seropositive was ostracized by family members. This resulted in the women living in social isolation from their family. They did not view their family as a source for social support. Several of the women did not say the word HIV. They considered the word HIV to be offensive and carry a negative connotation. One woman shared that she does not say HIV. She does not like to be called a person living with HIV. She stated the only time she talks and mentions HIV is when she has clinic visit. Several women mentioned, when they were diagnosed with this [HIV] or my [HIV] status, these women also shared that HIV

medication is a constant reminder for them of having the virus not living with the virus and wellness.

Social support for the women was shaped by a complex matrix comprised of who was present when they learned about their status, their personal histories with HIV among family and friends, as well resources for emotional and financial support. These factors were conveyed in the women's narratives which tended to be shaped by age and length time of diagnosis. Some women shared how they had received support from family and friends who attended medical appointments. Some talked about the love that they had received from family by being invited to as well as hosting family events. Others talked about the importance of having a person to talk to who was trustworthy, which was viewed as a key factor in accepting their HIV status.

#### *Disclosure*

All the participants struggled with the dilemma of sharing their HIV status with their sexual partner or the right to privacy and confidentiality. Even after a diagnosis where the partner was not present for their initial diagnosis, women felt the need to be discrete about their status, not knowing if their partner was responsible for transmitting the virus to them, how their partner would respond or where to place responsibility. A few women did not disclose until after a sexual encounter occurred that they were HIV-positive. The women shared they had a sense of protection of the health of others but exercised autonomy in what they defined as protection. Some women made the decision to share their status and then allow the sexual partner the option to use or not use a condom during intercourse; other women did not disclose their status but were persistent that if a condom was not used no sexual activity would take place. None of the women

explored the possibility that if they were aware of their partner's status or if their partner was aware of their status, would the decision to engage in sexual activity, sexual activity without protection and the decision about pregnancy be changed. The women all described feelings of devastation with the thought of infecting a partner.

As an alternative to condoms, several of the women expressed knowledge and interest of PrEP for their partners. Partner communication and disclosure of status are strongly recommended by HIV testing counselors, however partner communication related to the a positive partner preventing HIV did not appear to influence safe sexual practices in one study of women living with HIV (Haddad et al., 2018). Women face a dilemma with consistent condom use with their partner related to power (Dixon-Mueller, 1993; Farrington, Bell, & DiBacco, 2016; Soler et al., 2000). Women in this study valued their partners' interest and willingness to take PrEP. Women expressed how they viewed virologic suppression as decreasing the risk associated with transmitting HIV to their partner, vindicating their occasional unprotected sexual encounters and demonstrating if they experienced or planned a pregnancy their infant would be safe. Others reported when they had high levels of viral activity which caused physical symptoms like weakness, tiredness and ulcers, they did not engage in sexual activities.

Although women reported they had difficulty psychologically, financially and at times with access to care, the women were not fond of using social services resources despite having qualified because of their HIV status. This was shared in several of the narratives. Women shared if they used social services resources, they will have to disclose their status. Many did not want to do this. One of the participants and her partner

are seropositive. Despite knowing she can receive aid to end her homelessness, she continued to stay with relatives due to fear of disclosure.

Women's ability to safely disclose their HIV status was tied to the timeliness of sexual encounters, risk of abandonment and the degree in which the women were accepting of their HIV-positive status. Women varied in the timeliness of the sexual encounter. Several of the women stated they abstained from sexual activity for months while getting to know a partner or when a partner showed affection or interest in being sexually intimate. Other women reported that things would happen so quickly, they found themselves in situations where discussions of contraception and condom negotiation occurred moments before a sexual encounter. Women stated that in such situations they held a strong stance that they would not continue to engage in having sex if the person did not have a condom. Women also shared that there were times when sexual situations were not always manageable, and they would proceed with having sex.

Other women expressed that they felt an obligation to tell any potential sexual partner that they were HIV-positive. Several of the women expressing this conviction reported either being in monogamous relationship for several years or were currently married. Others who were not currently in a relationship reported that they had sustained years of being abstinent because they did share their HIV status. Some women who reported not disclosing their HIV status resulted in a potential sexual partner declining to proceed in having sex with them but remain friendly. The common view of all the women was disclosing their HIV status was a very vulnerable moment faced with the challenges of the possibility that their relationship was at risk; putting a potential sexual partner at risk; and the question did their partner share their status. Some women were

more comfortable and accepting of their status and displayed their ability to disclose their status with anyone. These women expressed that they had accepted that people have a choice in how they choose to respond to them. Women shared how taking this stance made them feel stronger. Three women shared that they had been situations when a person shared their seropositive status in a room filled with people. Each of the three women who shared this experience commented on how seeing someone who had overcome the barriers of HIV stigma made them feel good. Each woman also expressed feeling a sense of remorse and embarrassment for the people who had publicly disclosed their status. The experience of seeing how others respond to someone who discloses that they are seropositive resonated with women and reinforced in them that HIV stigma is hurtful and to be avoided, not lived with. From an epistemological perspective, for these women coping was the ability to share and the ability to remain silent.

Several women commented on their experience with HIV testing. Several women were not screened for HIV until the late stage of pregnancy. Notable, the health providers for these women did not reach out to the men who were their sexual partners. All the women who reported being tested positive during pregnancy expressed their initial shock upon hearing that they were seropositive. Some women described how they felt when they received the results of their HIV tests by way of a phone call. Some shared how they contained themselves emotionally by thinking about the possibility that sometimes tests were bundled with other tests. Some expressed that their initial thought was that they were receiving information that was related to a problem with their pregnancy or fetus. One woman reported calling her partner, another shared that she called her mother,

both were asked be present to hear about the doctor's concern. They were shocked when they found out that the purpose of the call was about their HIV status.

One woman described her experience of testing as discourteous. She shared that she was asked a health provider about her pregnancy and status of physical health because she was further in her pregnancy. She shared "of course [this is something] I do. The women shared that upon asking her health provider for information the counselor responded, well did you know you were HIV-positive too. This woman went on to describe how the response from the counselor made her feel so isolated and that she was so shocked that she did not know how to respond. These experiences underscore the important role that health services play in a woman's decision to consent to HIV testing during pregnancy (Lee King & Pate, 2013). Studies evidence that women who engage in pregnancy discussions with their health care providers and are enrolled in HIV care and treatment services experience a fewer unplanned pregnancies than women who do not engage in pregnancy discussions and are linked to HIV care (Rahangdale et al., 2014).

Some women who were in long-term monogamous relationships described that knowing their status empowered them to encourage their partner to be tested. The women described that their partners were not always responsive, but eventually they were tested. Among three of the cases, the partners were HIV-positive. There were instances in which women described disclosing their seropositive status with sexual partners and the men elected to not use a condom. In these situations, the women did not ask the men about their status, testing history, or concern about their own risk of exposure. In these situations, HIV became persona non grata. These women shifted their attention from

protecting their sexual partner to allowing their partner to take full responsibility for the risk of HIV infection.

### *Health care*

The women were all long-standing and established patients at referring clinics. Many of the women described trust, positive interactions and support from their care providers. The majority women described their provider's reassurance that they can have a healthy pregnancy, their provider's interest in their pregnancy intentions and the consistent message to use contraception. Women who were younger than age thirty reported that they would talk to their provider about family planning. Some said that their partners had expressed an interest in wanting to have a child in the future. Women who said that they had no intentions of becoming pregnant shared that they had had discussions with their health care providers about permanent sterilization.

Women reported that they were not always compliant with their antiretroviral regimens before and after pregnancy. Similar to other studies exploring barriers to adherence, the women in this study all described their being non-adherence being influenced by food insecurity, stigma, depression, pill burden, and fear of family, church, and community ostracization (Chop et al., 2017; Hodgson et al., 2014; Nachege et al., 2014; Spaar et al., 2010; Turan et al., 2017). Noteworthy, one woman in the study is a long-term survivor of HIV, is known as functionally cured but her immune system allows for control of viral replication and total reduction of the symptoms infection despite her not taking antiretroviral therapy (Liu, Ma, Liu, Chen, & Zhang, 2015).

## Evidence of Quality

In this study, the researcher ensured investigator triangulation and peer debriefing which involves working in conjunction with two or more researchers in the same study to provide various observations and assumptions (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Throughout the study, the researcher sought support from her dissertation committee, clinical staff, and academic administration. Negative case analysis was used to explore new information that was shared but did not appear in other interviews prior to saturation occurring (Lincoln, Guba, & Pilotta, 1985).

Thick description establishes the ability for a study to be transferred to other populations, case-by-case (Nowell, Norris, White, & Moules, 2017; Tobin & Begley, 2004). In this study the use of thick description was used to establish themes and make analytical conclusions through soliciting a description of unintended pregnancy from the women in the study, analyzing the narratives and reviewing diverse research paradigms to inform if what was described by the women was substantiated or unnoticed in social research.

Lastly, reflexivity is the act of being present and analytical to the context of knowledge building, especially as it effect the researcher, throughout the entire process (Lincoln et al., 1985). Throughout the study, the researcher examined research questions, probes and follow-up to questions asked ad hoc during interviews, through writing memos and field notes explored how the researcher's perspective may be restricted, and how she may be prone to bias.

### Strengths

This study explores the experiences of unintended pregnancy and HIV using the in-depth analysis of narratives from African American women of child bearing age living with HIV. The findings contribute to sexual and reproductive health research among HIV-positive people, specifically African American women. This study coincides with findings from previous research surrounding the socioeconomic characteristics of women who are at risk for an unplanned pregnancy and individual risk factors associated with HIV transmission (Henshaw, 1998; Kost, 2015; Sonfield & Kost, 2015). This study provides insight into a women's experience with pregnancy, intimacy, learning about her status and navigating socio-ecological systems to live with HIV.

### Limitations

The findings of this research are within the context of several limitations. This study sampling procedure included women who were suggested by and enrolled from clinical sites with referral assistance from team members, as such, self-selection bias exists. The goal of this research was to explore unintended pregnancy from the experience of urban African American women who seek services from three specific clinics located in Philadelphia, therefore, the results are limited to the population. An important feature of grounded theory is that it does not require the researcher revisit with participants to ensure participants agree with the researcher's findings ((Strauss, 2015). However, respondent validation, which was not conducted in this study, produces another data, which can be analyzed to ensure respondent validation and decrease subjectivity. This step would have strengthened this study.

## Implications for Future Research

Several areas emerged through this exploratory study requiring further investigation. Further study is needed to characterize the types of beliefs, attitudes, and cultural beliefs on pregnancy intentions across the childbearing age timeframe among seropositive African American women. Additionally, further attention is required to understand facilitators and barriers to casual and long-term intimate partner disclosure. Lastly, health providers play a critical role in women's health. Further attention is required in exploring the various forms of gender bias that may contribute to the health disparities among African American women. Further attention is required to how gender bias influence health care providers linkage and engagement of the sexual partners of seropositive women in the HIV continuum of care. Results demonstrate the importance of bringing awareness to HIV testing, disclosure, stigma and behavioral health treatment. In particular, interventions and skill building to ensure practitioners are advocates for testing and establishing connections for women to consider the role of these factors as it relates to barriers or stressors to wellness are needed.

## Conclusion

While pregnancy intentions are vastly quantitatively discussed, knowledge related to pregnancy definitions expressed by African American women is limited. Women who are most affected by both HIV and unintended pregnancy literature and public health goals are African-American women. Allowing the voices of women to be heard in this study contributes to the limitations of this body of literature. The proposed descriptive theoretical model provides a conceptual model for defining unintended pregnancy and describing specific characteristics of unintended pregnancy experienced by seropositive

women. The findings offer insights into the phenomena of unintended pregnancy characterized as a complex process influenced by age, psychological, cultural, and social environmental factors. The valence of this complex, multifaceted process for successfully navigating the challenges of being an African American woman who is seropositive is influenced by her resilience, social supports, protecting others and her health care provider relationship. As progress continues in biomedical strategies for prevention and treatment of HIV, our success in reducing health disparities among African American women of child bearing age is determined by how well we integrate reproductive health with HIV care and treatment strategies.

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APPENDIX A: TABLES

Table 1

*Grounded Theory Coding Process (Glaser, 1978)*

Coding	Process	Outcome
Open Coding	Process of breaking down data, examining what the overall aims of the study is and what is happening in the data, comparing, conceptualizing and categorizing data	Open coding consists of: <ul style="list-style-type: none"> <li>• Labelling phenomena</li> <li>• Discovering categories</li> <li>• Developing categories, properties and dimensions</li> <li>• Several concepts</li> </ul>
Axial Coding	Data is combined to form new categories, examine the relationship of subcategories to create hypothesized connections that are supported by new data or a new analysis of the data	Axial coding consists of: <ul style="list-style-type: none"> <li>• Taking categories and identifying relationships and establishing conditions that give rise to the category</li> </ul>
Selective Coding	The process of selecting the core category, the central category around what the final analysis will be based, then relating the analysis to other categories	Selective coding consists of: <ul style="list-style-type: none"> <li>• Explicating the story line: analytic description of the core category</li> <li>• Relating other categories to the core</li> <li>• Validating the story line</li> <li>• Validate the theory against the data</li> <li>• Write a series of memos that step through the story</li> </ul>

Table 2

*Recruitment Site Characteristics*

Recruitment Site	Locations	Overview of Services	Recruitment Point Person
Site 1	2 locations	Hospital system that specializes in Pediatric and Adolescent HIV, primary medical care for pediatric and adolescent patients with HIV/AIDS, as well as care for affected family members including adults. Offers treatment for high risk HIV exposure through non-occupational post-exposure prophylaxis (nPEP) and pre-exposure prophylaxis (PrEP). Primary and specialty HIV/AIDS care is available for HIV-exposed newborns and HIV-positive infants.	2 Doctors 1 Research Assistant
Site 2	1 location	Academic institution, part of a hospital systems' Immunology Program within the Division of Infectious Diseases and Environmental Medicine. Provides primary care and is designated to participate in clinical trials.	1 Doctor 2 Research Assistants
Site 3	3 locations	Community organization that offers comprehensive health services including primary care, consumer education, research, and advocacy for people living with HIV/AIDS and those at high risk; has five HIV specific clinic locations, one specifically for women.	Executive Director Research Director

Table 3

*Selected Participant Demographics*

Participant	Age	Age at Diagnosis	Pregnancy with HIV	Previous Pregnancy	Children Ages	Education Level	Marital Status	Income	Adherence
Marie	30	17	3, 1 miscarriage	1	15, 8, 6	Some College	Married	20-30K	Poor, A little of the time, 50%
Cheryl	39	16	5, 1 miscarriage	0	23, 21, 14, 2	Highschool Diploma	Single	20-30K	Fair, A good bit of time, 70%
Shay	33	19	0	0	0	Less than Highschool	Single	10-20K	Excellent, All the time, 100%
Sade	31	19	1, lost a child	2	11	Highschool Diploma	Single	10-20K	Very Good, Most of the Time, k90%
Lilly	24	Born	0	0	0	Some College	Single	10-20K	Excellent, Most of the time, 90%
Shana	21	17	0	0	0	Highschool Diploma	Single	-10K	Excellent, All the time, 90%
Joy	25	Born	0	0	0	Highschool Diploma	Monogamous Relationship	-10K	Excellent, All the time, 100%
Angel	30	23	2	0	7 deceased 1	Highschool Diploma	Living with a partner	-10K	Fair, Most of the time, 100%
Rahvens	32	22	2	0	9, 7	Less than Highschool	Engaged	-10K	Excellent, All the time, 100%
Markel	47	32	2	9	30, 27, 26, 22, 21, 19, 18, 15, 13	Highschool Diploma	Married	10-20K	Fair, All the time, 100%
Sharon	39	37	0	6	23, 22, 18, 14, 15, 11	Highschool Diploma	Single	-10K	Excellent, All of the time, 100%
Hope	28	14	2	0	8, 1	Highschool Diploma	Single	10-20K	Excellent, A good bit of the time, 80%

Table 4

*Coding Families (adapted from Glaser 1978: 75–82)*

Coding Families	Examples
The Six C's	Causes (sources, reasons, explanations, accountings or anticipated consequences), Context or Ambiance, Contingencies, Consequences (outcomes, efforts, functions, predictions, anticipated/ unanticipated), Covariances, Conditions or Qualifiers.
Process	Stage, Staging, Phases, Phasing, Progressions, Passages, Gradation, Transitions, Steps, Ranks, Careers, Ordering, Trajectories, Chains, Sequencing, Shaping, Cycling.
Dimension	Dimensions, Elements, Divisions, Piece of, Properties of, Facet, Slice, Sector, Portion, Segment, Part, Aspect, Section.
Type	Type, Form, Kinds, Styles, Classes, Genre.
Strategy	Strategies, Tactics, Mechanisms, Managed, Way, Manipulation, Maneuvering, Dealing with, Handling, Techniques, Ploys, Means, Goal, Arrangements, Dominating, Positioning.
Interactive	Mutual Effects, Reciprocity, Mutual Trajectory, Mutual Dependency, Interdependence, Interaction of effects, Covariance [GLASER78], Face to Face Interactions, Self-indications, Delayed-interaction [GLASER98, Symbolic Interaction].
Identity-Self	Self-image, Self-concept, Self-worth, Self-evaluation, Identity, Social worth, Self-realization, Transformation of self, Conversions of identity.
Cultural	Social norms, Social values, Social belief, Social Sentiments.
Mainline	Social control, Recruitment, Socialization, Stratification, Status passage, Social organization, Social order, Social interaction, Social mobility.
Unit	Collective, Group, Nation, Organization, Aggregate, Situation, Context, Arena, Social world, Behavior pattern, Territorial Units, Society, Family.

Table 5

*Open Coding Themes Developed from Qualitative Transcripts*

Name	Files	References
Profiles of HIV	8	18
Stigma	10	19
Culture	6	20
Religious Reference and Pregnancy	5	12
Family and Pregnancy History	6	14
Pregnancy Outcome	8	25
Fear	4	7
Other People's Responses to Pregnancy	10	14
Planned Pregnancy	11	35
Unintended Pregnancy	12	27
Untimed Pregnancy	10	12
Experience with Unplanned Pregnancy	8	25
Living with HIV	11	38
Medication Adherence	6	10
Antiretroviral	9	15
During Pregnancy	10	24
Community Resources	9	17
Healthcare	9	23
HIV Diagnosis	10	27
Unknown Status	5	9
Initial Reaction	8	15
Mental State	11	32
Stress	11	24
Coping	10	31
Infecting a partner	10	39
Contraception	12	40
Avoiding Pregnancy	3	3
Adherence to Contraception	5	5
Access to Contraception	9	9
STI's	7	16
Condom negotiation	8	18
Barriers to Contraception	10	23
Risk	10	24
Condoms	9	25
Support System	12	47
Attitude towards Pregnancy	12	48
Age and Pregnancy	6	13
Thoughts of Pregnancy	4	14
Partners Desire	5	15
Attitude towards partner	5	9
Desire to Become Pregnant	8	20
Pregnancy Possibility	9	22
Readiness for Parenting	9	25
HIV and Pregnancy	10	30
Healthy Pregnancy Definition	8	13
Knowledge of HIV and Pregnancy	8	20
HIV Disclosure	13	78
Disclosure to Child	6	8
HIV Positive Child	1	1
Accidental Disclosure	7	11
Disclosure to Sexual Partner	10	29
HIV Positive Partner	5	14

Table 6

*Sample Axial and Selective Coding*

Name	Axial Coding Family	Selective Coding	Files	Reference
HIV Disclosure	Six C's	Outcomes of Sharing Status	13	78
Attitude towards Pregnancy	Six C's	Pregnancy	12	48
Support System	Strategy	Outcomes of Sharing Status	12	47
Contraception	Interactive	Sense of Protection	12	40
Unintended Pregnancy	Six C's	Pregnancy	12	27
Living with HIV	Strategy	Resilience	11	38
Planned Pregnancy	Six C's		11	35
Mental State	Strategy		11	32
Stress	Type		11	24
Infecting a partner	Interactive	Sense of Protection	10	39
HIV and Pregnancy Disclosure to Sexual Partner	Interactive		10	30
			10	29
Barriers to Contraception		Sense of Protection	10	23
Stigma		Outcomes of Sharing Status	10	19
Other People's Responses to Pregnancy	Interactive		10	14
Untimed Pregnancy	Six C's		10	12
Community Resources	Mainline		9	17
Antiretroviral			9	15
Access to Contraception			9	9
Experience with Unplanned Pregnancy			8	25
Pregnancy Outcome	Interactive	Resilience	8	25
Mother- Description of Self	Identity- Self		8	21
Desire to Become Pregnant	Degree		8	20
Knowledge of HIV and Pregnancy			8	20
Condom negotiation			8	18
Profiles of HIV	Cultural		8	18
Initial Reaction			8	15
Provider Communication	Interactive		8	14
Healthy Pregnancy Definition			8	13
Coping			7	22
STI's			7	16
Parent Child Relationship	Interactive		7	15
Accidental Disclosure			7	11
Culture	Cultural	Resilience	6	20

Table 7

*Theme 1: Resilience Coding Table*

Name	Files	References
Culture	6	20
Experience with Unplanned Pregnancy	1	1
Family and Pregnancy History	5	13
Religious Reference and Pregnancy	4	10
Living with HIV	11	38
Community Resources	8	16
Healthcare	8	21
Coping	1	8
HIV Diagnosis	10	27
Initial Reaction	8	15
Unknown Status	5	9
Medication Adherence	5	8
Antiretroviral	8	9
During Pregnancy	9	22
Mental State	10	25
Coping	9	23
Stress	10	20
Pregnancy Outcome	8	25
Fear	4	7
Other People's Responses to Pregnancy	9	12
Planned Pregnancy	10	26

Table 8

*Theme 2: Outcomes of Sharing Status Coding Table*

Name	Files	References
HIV Disclosure	13	78
Accidental Disclosure	7	11
Disclosure to Child	6	8
HIV Positive Child	1	1
Disclosure to Sexual Partner	10	29
HIV Positive Partner	5	14
Stigma	10	19
Support System	12	47

Table 9

*Theme 3: Sense of Protection Coding Table*

Name	Files	References
Contraception	12	40
Access to Contraception	9	9
Adherence to Contraception	5	5
Avoiding Pregnancy	3	3
Barriers to Contraception	10	23
Condom negotiation	8	18
Condoms	9	25
Risk	10	23
STI's	7	16
Infecting a partner	10	39

Table 10

*Theme 4: Pregnancy Coding Table*

Name	Files	References
Attitude towards Pregnancy	12	48
Age and Pregnancy	5	11
Desire to Become Pregnant	8	20
HIV and Pregnancy	9	24
Healthy Pregnancy Definition	7	10
Knowledge of HIV and Pregnancy	7	16
Partners Desire	5	15
Attitude towards partner	5	9
Pregnancy Possibility	9	22
Readiness for Parenting	9	25
Thoughts of Pregnancy	4	14
Unintended Pregnancy	12	27
Experience with Unplanned Pregnancy	7	24
Untimed Pregnancy	10	12

## APPENDIX B: INTERVIEW QUESTIONS

### Questions

Tell me a little about yourself

### **There are a couple of questions I have about different words/terms and how you would define them.**

What does the term unintended pregnancy mean to you?

What are your thoughts about an untimed pregnancy?

How would you describe a planned pregnancy?

### **What would you imagine/ what have you heard?**

Tell me your thoughts about pregnancy and living with HIV.

If you discovered, you were pregnant right now how do you think you would react?

Tell me about your experience with pregnancy (if you have any or pregnancy scares if not).

Can you tell me about a time when you thought about becoming pregnant? /Tell me about your views about becoming a mother or being a mother?

### **Talk a little about people in your life.**

How would you describe your support system?

Percentage of PLHA who have disclosed their status beyond a few trusted individuals and who have disclosed within 6 months of learning his/her status.

- Have you told anyone about your HIV status?
- Who have you told?
- How soon after learning your HIV status did you disclose your status to these specific people?

Percentage of PLHA who have disclosed their HIV sero-status to their primary sexual partner.

- Who have you told?
- Percent of PLHA whose HIV status has been disclosed without their consent.
- Has your HIV status ever been revealed without your consent?

What would people in your life think if you became pregnant?

Is there anyone in your family that you would tell last.

How likely do you think it is that you could have an unintended pregnancy now in your life?

There are a lot of women out there that don't plan on becoming pregnant, can you tell me why you think that is?

In the future can you see yourself becoming pregnant?

What have you heard about HIV medication and pregnancy?

### **Your daily life questions.**

What's it like living with HIV?

What's it like living in HIV as a woman living in Philadelphia?

**Probe: I've heard from other women, hard living with HIV, money for medication, getting to the doctor**

What makes it difficult to live with HIV?

What can create stress for women with HIV who are pregnant?

**Shift now and talk about how to avoid pregnancy and other topics**

What's your personal experience with contraception?

Tell me about your views on contraception.

What influences you to use or not use protection against pregnancy (How do you decide to use protection or not)?

Can you get contraception if you want it?

What has been your greatest challenge related to protection?

We talked about pregnancy, tell me about your thoughts about other STI or giving HIV to someone what are your concerns.

Could you tell me about a healthy pregnancy for a woman living with HIV?

Tell me about community resources that are available for women living with HIV who would like to start a family.

Is there anything else we should have asked about?

**Demographic Questions**

*What is your age?*

\_\_\_\_\_years

*What is the highest level of school you have completed or the highest degree you have received?*

*1 High school incomplete or less*

*2 High school graduate or GED (includes technical/vocational training that doesn't count towards college credit)*

*3 Some college (some community college, associate's degree)*

*4 Four year college degree/bachelor's degree*

*5 Some postgraduate or professional schooling, no postgraduate degree*

*6 Postgraduate or professional degree, including master's, doctorate, medical or law degree*

*Which of these best describes you?*

*1 Married*

*2 Living with a partner*

*3 Divorced*

*4 Separated*

*5 Widowed*

*6 Never been married*

*7 In a monogamous relationship*

*8 Friend with benefits*

*How many people, including yourself, live in your household?*  
\_\_\_\_\_people

*How many, including yourself, are adults, age 18 or older?*  
\_\_\_\_\_adults

*Are you the parent or guardian of any children under 18 now living in your household?*  
1 Yes  
2 No

*What are the ages?How many children do you have living?*

*How many pregnancies?*

*What is your faith?*

*Aside from weddings and funerals, how often do you attend religious services?*  
1 More than once a week  
2 Once a week  
3 Once or twice a month  
4 A few times a year  
5 Seldom  
6 Never

*Last year, that is in 2017, what was your total family income from all sources, before taxes?*

- 1 Less than \$10,000
- 2 \$10,000 to less than \$20,000
- 3 \$20,000 to less than \$30,000
- 4 \$30,000 to less than \$40,000
- 5 \$40,000 to less than \$50,000
- 6 \$50,000 to less than \$75,000
- 7 \$75,000 to less than \$100,000
- 8 \$100,000 to less than \$150,000
- 9 \$150,000 or more

*Which of these statements best describes you?*

- 1 You are **ABSOLUTELY CERTAIN** that you are registered to vote at your current address
- 2 You are **PROBABLY** registered, but there is a chance your registration has lapsed
- 3 You are **NOT** registered to vote at your current address

*Do you own or rent your home?*

- 1 Own
- 2 Rent
- 3 Other arrangement

*At what age were you diagnosed with HIV?*

*Do you know someone in the past year who has had the following happen to him/her because of HIV or AIDS?*

1. Excluded from a social gathering.
2. Lost customers to buy his/her produce/goods or lost a job.
3. Had property taken away.
4. Abandoned by spouse/partner.
5. Abandoned by family/sent away to the village.
6. Teased or sworn at.
7. Lost respect/standing within the family and/or community.
8. Gossiped about.
9. No longer visited, or visited less frequently by family and friends.
10. Visitors increase to “check them out.”
11. Isolated within the household.

*In the last year, have you [fill in from list below] because of your HIV status?*

1. Been excluded from a social gathering.\*
2. Been abandoned by your spouse/partner.
3. Been isolated in your household.
4. Been no longer visited or visited less frequently by family and friends.
5. Been teased, insulted or sworn at.
6. Lost customers to buy produce/goods or lost a job.
7. Lost housing or not been able to rent housing.
8. Been denied religious rites/services.
9. Had property taken away.
10. Been gossiped about.
11. Lost respect/standing within the family and/or community.
12. Been threatened with violence.
13. Been given poorer quality health services.
14. Been physically assaulted.
15. Been denied promotion/further training.
16. Had an increase of visitors to “check out” how you are doing.
17. Been abandoned by your family.

Rating (RATING)

Thinking about the past 4 weeks, on average, how would you rate your ability to take all your medications as your doctor prescribed them?

Response options

very poor, poor, fair, good, very good, excellent.

Frequency (FREQ)

Thinking about the past 4 weeks, how often did you take all your HIV antiretroviral medications as your doctor prescribed them?

Response options

none of the time, a little of the time, a good bit of the time, most of the time, all of the time.

Percent (PERCENT)

Thinking about the past 4 weeks, what percent of the time were you able to take all your medications as your doctor prescribed them?

Response options

0%, 10%, 20%, 30%, 40%, 50%, 60%, 70%, 80%, 90%, 100%.

APPENDIX C: FIELD NOTES SHEET

**Field Notes**

**Protocol Title**

Exploring Unintended Pregnancy among Urban Black Women Living with HIV/AIDS

**Investigator**

Nadia Glenn (Student)  
Larry Icard, PhD (Chair)

**Date:**

**Location:** \_\_\_\_\_

**Time:** \_\_\_\_\_

**Study ID:**

Weather:	
Location of the study:	
What is clinic near?	
Geographic features that affect health or access to health care:	
Location of recruitment efforts:	
Location of interview (Describe the room where the interview took place, the location of the participant compared with the interviewer, and any relevant room features or items.)	
Absence of features:	
Demographics of the overall area where clinic and interview take place (distribution, mean and median age, and educational level in the community as well as race and ethnicity data, common careers, major employers)	
Describe any people present and note whether they consented to have their comments included in the study.	
<b>Participant</b>	
<b>Appearance</b>	
baseline nonverbal behaviors include hand wringing, dermatillomania, or lack of eye contact.	
Discuss participant response to the interview as a whole, noting any overarching nonverbal behaviors.	
<b>Questions</b>	
Note any changes to the interview questions and the reasons the questions were adapted for this setting.	
Critical reflection. After noting pertinent details of the interview, spend a few moments intentionally reflecting on the whole of the interview and your performance as a participant in the narrative and as an interviewer.	

## APPENDIX D: LETTER OF SUPPORT



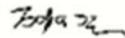
May 10, 2018

Dear Nadia Glenn,

The Partnership Comprehensive Care Practice is happy to support your dissertation research proposal, *Exploring Unintended Pregnancy among Urban Black Women Living with HIV/AIDS* to explore unintended pregnancy among African American women living with HIV. As an organization that is committed to providing primary care, consumer education and advocacy for individuals that are living with or affected by HIV/AIDS, exploring pregnancy supports our mission. We strongly support your research and the focus on this important topic.

Through this letter, we acknowledge our role to support recruitment efforts and assist you in reaching the targeted population. We look forward to working with you and supporting future leaders in the field of HIV/AIDS and public health.

Sincerely,



Zoşia Szep, MD, MSCE  
Associate Professor of Medicine  
Medical Director  
Partnership Comprehensive Care Practice  
Division of Infectious Diseases and HIV Medicine  
Drexel University

## APPENDIX E: STUDY CONSENT FROM

Permission to Take Part in a Human Research Study

Page 1 of 2

*Title of research: Exploring Unintended Pregnancy among Urban Black Women Living with HIV/AIDS*

*Investigator and Department: Larry Icard, PhD College of Public Health, School of Social Work*

***Why am I being invited to take part in this research?***

We invite you to take part in a research study because you stated you are an African American woman between the ages of 21-49, speak English, are HIV-positive and do not have a device that prevents pregnancy like an IUD or implant or had a procedure where now you are not able to become pregnant (like having your tubes tied).

***What should I know about this research?***

- Someone will explain this research to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

***Who can I talk to about this research?***

If you have questions, concerns, or complaints, or think the research has hurt you, contact the research team at **Nadia Glenn, [ncorbin@temple.edu](mailto:ncorbin@temple.edu), 610-400-9139**

This research has been reviewed and approved by an Institutional Review Board. You may talk to them at (215) 707-3390 or e-mail them at: [irb@temple.edu](mailto:irb@temple.edu) for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

***Why is this research being done?***

Services for HIV-positive women to learn about and receive contraception, antiretroviral therapies and prenatal care are available, while services and information that focus on a healthy and timely pregnancy are not as available. There is little information available that talk about pregnancies that are not planned among HIV-positive women. This research will build explore pregnancy among African American women living with HIV.

***How long will I be in this research?***

We expect that you will participate in this interview no more than 2 hours.

***What happens if I agree to be in this research?***

If you agree to be in this study the following will occur:

- Nadia Glenn will spend time with you and talk to you about your everyday life. Some of our conversations will include discussions of your daily life, relationship, sexual activity, pregnancy intentions, children, social and community affairs, health, family values and past experiences.
- With your permission, this conversation will be recorded.
- A written interpretation (transcript) will be produced from the recording by an outside company that agreed to confidential rules. The transcript of the interview will be analyzed by Nadia Glenn. Access to

Document Revision Date: July 6, 2017

## APPENDIX F: RECRUITMENT ADVERTISEMENT



### UNINTENDED PREGNANCY

The purpose of this research study is to understand unintended pregnancy among women who are living with HIV.

#### Contact Information

To find out more about this study, please contact:

- Larry Icard, Principal Investigator
- Call Nadia Glenn 610-400-9139

### TO PARTICIPATE IN THIS RESEARCH YOU MUST BE:

- A woman
- Age 21-49
- English speaking
- African American
- Living with HIV
- Do not have a permanent contraceptive method (tubal ligation or intrauterine device) and are not pregnant.

### PARTICIPATION INVOLVES:

- One time in person interview
- Expenses covered for transportation and time commitment

This study is strictly confidential.

