The Social Determinants of Health for African American Mothers Living with HIV

by

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Duke University

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Anh Nhat Tran

Dissertation submitted in partial fulfillment of
the requirements for the degree of Doctor
of Philosophy in Nursing in the Graduate School
of Duke University

2015
ABSTRACT

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Abstract

**Problem:** The disparate health outcomes of African American mothers living with HIV functions at the intersection of gender-, race-, and class-inequality; HIV-related stigma; and motherhood, requiring multidimensional approaches to address the complex social and economic conditions of their lives, collectively known as the social determinants of health. African American women suffer significantly higher HIV infection rates and tend to die earlier from their infection than their White counterparts. Poverty is a significant precipitating factor for HIV infection and African American women are disproportionately poorer than other subpopulations in the United States. HIV-related stigma is linked to poorer mental and physical health outcomes across a broad range of demographic profiles. Being a mother adds an extra layer of social complexity to the lives of women living with HIV. This dissertation was designed to develop knowledge on the social determinants of health for African American mothers living with HIV by describing their social location at the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood and exploring how their unique social identity influences their health-related experiences.

**Methods:** Using data from a literature review on intersectional approaches and other frameworks for examining vulnerable populations, an intersectional model for the study of the social determinants of health for African American mothers living with HIV
was constructed. A pilot study exploring the methodological issues and ethical challenges of using photo elicitation with a highly stigmatized social group of women was conducted. The intersectional model and pilot study findings were then used to guide a qualitative descriptive study using storyline graphs, photo elicitation and in-depth qualitative interviewing as methods for exploring the intersection of the social determinants of health for eighteen (18) African American mothers living with HIV. Content, vector and frame analyses were used to describe the intersection of social determinants and identify potential process and structural level interventions.

**Results:** Findings from the pilot study include best practices for using visual methods with a highly stigmatized and potentially vulnerable group of women. Findings from the qualitative descriptive study include six additional social determinants of health - social support, religiosity, animal companions, physical environment, transportation and housing - not initially included in the conceptual model, a case for strength-based approaches, intersecting social determinants functioning as systems of oppression and the heterogeneous and fluid social locations as framed from the mother’s perspective. Three frames of social location for African American mothers living with HIV were proposed – emancipatory, situational, and internalized – as well as potential health implications and interventions. Each of the findings add to the literature on the configuration of intersecting social determinants
health relevant to African American mothers living with HIV, expand the proposed intersectional model and help to generate hypotheses needed for intervention studies.
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1. Introduction

1.1 Problem

Disparities in the health outcomes of persons living with HIV across racial, gender and socioeconomic groups have persisted into the third decade of the epidemic. These inequities are a focus of the National HIV/AIDS Strategy for the United States (2010) and President Obama’s 2012 mandate to examine the intersection of HIV/AIDS, violence against women and girls, and gender-related health disparities (Obama, 2012). Most intervention efforts to date have focused on individual risk behaviors for HIV, which are important, but can only partially explain disparities in health outcomes (Lane et al., 2004). Understanding the social and economic situations in which people live, collectively known as the social determinants of health, helps to uncover the processes interacting to produce significant and avoidable inequities in health outcomes (CSDH, 2008; Hankivsky, 2012). Experts estimate that social determinants represent three-quarters of all the factors contributing to population health, yet the majority of health interventions are targeted toward the smaller one quarter of determinants which include biological, genetic and behavioral factors (CDCP, 2014b; Tarlov, 1999). Findings from recent research reveal the critical role social determinants play in health outcomes and suggest that work focused only on individual risk behaviors and choices is no longer enough (Beltran, McDavid Harrison, Hall, & Dean, 2011; CDCP, 2010a; CSDH, 2008;
Lane et al., 2004). To that end, the World Health Organization released a report on the significance of the social determinants of health and urged the global community to recognize the need for action via monitoring, research and education (CSDH, 2008).

Understanding how the intersection of the social determinants of gender-, race- and class- inequality; HIV-related stigma; and motherhood impacts the health outcomes of HIV-infected African American mothers is essential to addressing their disparate health outcomes. Women now represent approximately one quarter of all the people living with HIV in the United States and most new infections are through heterosexual contact (CDCP, 2014a). African American women are 20 times more likely than White women to be newly infected with HIV (CDCP, 2015), and once infected, they are likely to die from AIDS earlier than their White counterparts (Losina et al., 2009). Reporting such statistics by categories of race or ethnicity, however, can obscure the impact of poverty (Ward, 1993). African American women are disproportionately poorer than other subpopulations in the United States (U.S. Census Bureau, 2012), and poverty is a significant precipitating factor for HIV infection (CDCP, 2010b).

Motherhood is of great consequence to women living with HIV and adds a layer of complexity to their lives that significantly impacts their health outcomes. A meta-synthesis of studies demonstrates that the primary goals of mothers living with HIV are to protect their children from HIV infection and HIV-related stigma (Sandelowski &
Barroso, 2003). These mothers describe higher levels of stress than non-mothers as they manage their own needs and the needs of their children in circumstances such as poverty (Jones, Beach, Forehand, & Foster, 2003). HIV-related stigma brings poorer mental and physical health outcomes across a broad range of demographic profiles (Logie & Gadalla, 2009). Mothers living with HIV experience difficulty as they attempt to carry out the daily activities of motherhood while experiencing profound fatigue and other physical limitations imposed by their disease (Murphy, Johnston Roberts, & Herbeck, 2011). Finally, the stigma associated with HIV/AIDS infringes upon their experience of motherhood (Sandelowski & Barroso, 2003). Mothers living with HIV desire to protect their children from HIV-related stigma and experience stress in regard to disclosure of their HIV status to their children, significant others and other family members, fearing that disclosure will make their children vulnerable to stigma (Sandelowski & Barroso, 2003). Mothers living with HIV also have concerns about the care of their children in case they become ill and die (Sandelowski & Barroso, 2003), yet paradoxically they cite motherhood and the desire to protect their children as a source of strength and a reason to live despite their infection (Wilson, 2007).

The scientific literature reveals that the vulnerability of African American HIV-infected mothers is a result of several social determinants of health, including: gender (Higgins, Hoffman, & Dworkin, 2010), race (Lane et al., 2004), class (CDCP, 2010b), HIV-
related stigma (Black & Miles, 2002; C. Kelly, Alderdice, & Lohan, 2009; Sandelowski & Barroso, 2003; Sanders, 2008; Wilson, 2007) and motherhood (Jones et al., 2003; Sandelowski & Barroso, 2003). For the sake of clarity and shared language, vulnerability will be defined as the “susceptibility to poor health” throughout this work (Shi & Stevens, 2010, p. 2). To my knowledge, however, no studies have specifically examined how these social determinants of health intersect to create this vulnerability.

Multidimensional and transdisciplinary approaches are needed to address the intersection of the complex social and economic conditions of these mothers’ lives.

Our efforts to keep HIV-infected mothers healthy have fallen short. Beyond the prevention of maternal to child transmission, the number of interventions targeted specifically to mothers living with HIV, with the goal of keeping them healthy is relatively small (Davies, Horton, Williams, Martin, & Stewart, 2009; Futterman et al., 2010; Glover, Garcia-Aracena, Lester, Rice, & Rothram-Borus, 2010; Jirapaet, 2000; M. S. Miles et al., 2003; Mitrani, McCabe, Robinson, Weiss-Laxer, & Feaster, 2010; Murphy, Armistead, Marelich, Payne, & Herbeck, 2011; Nelms & Zeigler, 2008; Oswalt & Biasini, 2011; Rotheram-Borus, Lee, Gwadz, & Draimin, 2001; Rotheram-Borus et al., 2003; Rotheram-Borus et al., 2011) and include such strategies as peer mentoring, stress/distress management, maternal self-care, HIV status disclosure, education or knowledge development, and positive parenting. These interventions studies are limited
by subject attrition (Futterman et al., 2010) primarily due to social determinants such as residential instability (Futterman et al., 2010) and HIV-related stigma (M. S. Miles et al., 2003). In addition, most of the interventions aimed at mothers living with HIV have focused on addressing individual risk behaviors rather than the social determinants of health.

Keeping HIV-infected mothers healthy and in care has broad public health implications. A recent landmark study indicates that early antiretroviral therapy is not only an important treatment strategy for HIV-infected persons and their partners but also an important public health strategy for reducing the transmission of HIV (M. S. Cohen et al., 2011). In other words, if patients remain in care, receive treatment and adequately suppress their viral loads, their risk of transmitting the virus is minimized. Interventions to effectively treat mothers living with HIV and keep them healthy will also have far-reaching implications for the health of their children. For example, a recent 12-year study of healthy children and HIV-infected mother dyads found that poorer maternal physical health status was strongly associated with negative outcomes for children, including depression, anxiety, aggression and poor self-concept (Murphy, Marelich, & Herbeck, 2012). For African American HIV-infected mothers, understanding the intersection of gender-, race- and class- inequality; HIV-related stigma; and
motherhood is essential to addressing their disparate health outcomes and informing future prevention and treatment efforts.

1.2 Background

1.2.1 Complexity of the Intersection

Intersectionality, grounded in the work of African American feminist social scientists (Hankivsky, 2012) and in related frameworks for examining vulnerable populations (Shi & Stevens, 2010) offers a means of examining intersecting social and economic circumstances and their roles in producing health inequities (Hancock, 2007; Hankivsky, 2012; U. A. Kelly, 2011; Shi & Stevens, 2010). Intersectionality does not assume that social determinants of health such as gender-, race- and class- inequalities simply accumulate to create a triple threat (Mullings & Schulz, 2006). Rather, the constructs vary as a function of one another depending on the particular gender, race and class to which an individual belongs (Mullings & Schulz, 2006). Scholars have described the ability of the constructs to vary as a function of one another as mutually-constituted (Hill Collins, 1998). In other words, the intersection of social determinants of health for an African American HIV-infected mother living in poverty may function quite differently than that of an African American HIV-infected father living in poverty. That is, race and class are gendered and may operate to produce different health outcomes (Mullings & Schulz, 2006). Again, for the sake of clarity and shared language, I
will use the language advanced by Patricia Hill Collins (1998), one of the scholars instrumental in the development of intersectionality, and use “mutually constituted” to describe this phenomena in this dissertation. Finally, but very importantly, intersectionality challenges the idea of gender as the primary dimension of inequity or social determinant of health; rather, it acknowledges multiple dimensions of inequity that can shape health experiences (Hankivsky, 2012).

1.2.2 Conceptual Framework

The conceptual framework that will guide this dissertation is based on a model titled Motherhood and HIV: An Intersectional Approach. Central to this model (Figure 1) is the concept of vulnerability, defined as a “susceptibility to poor health” (Shi & Stevens, 2010, p. 2).
Figure 1: Motherhood and HIV: An Intersectional Approach

The model represents the intersection of specific factors as mutually constituted (Hankivsky, 2012; Hill Collins, 1998; Mullings & Schulz, 2006) vulnerability in which these factors jointly determine health status and access to quality health care. To illustrate, the conceptual relationships in the intersectional model (Figure 1), a woman living with HIV is standing at a large traffic intersection with her children in tow. Her challenge is to cross the intersection safely, protecting both herself and her children. In the model, 1) the social determinants of health (represented by roads) intersect to create a mutually constituted vulnerability; 2) the larger the intersection (i.e., the more vulnerabilities), the more difficult the woman’s task of managing her condition and
accessing quality health care, leading to a greater likelihood of poor health outcomes; 3) gender, race and class are viewed as socially constructed categories, rather than biological or genetic attributes of individuals (Mullings & Schulz, 2006); 4) motherhood (represented by a bridge) may positively influence the ability of a woman living with HIV to navigate the intersection and her subsequent health outcomes; and 5) the health outcomes of the children are at least partially dependent on the health outcomes of the mother and her ability to navigate the intersection.

To be sure, one of the challenges with intersectionality, or an intersectional approach, is the difficulty of bridging the gaps between the complex theoretical stance of mutually constituted social determinants of health, sound methodology to test the concepts and conceptual relationships asserted by the approach and practical efforts to ameliorate health inequities (McCall, 2009). In this study alone, there is conceivably a minimum of four or five social constructs of interest emerging from the literature that intersect to form the mutually constituted vulnerability of African American mothers living with HIV. Following is rationale for the methodological approach I propose to use in order to bridge this gap from theory to praxis.

1.3 Approach

To explore the complexity of the social constructs outlined above and their relationships, I will use an interpretive approach and qualitative data collection methods
of in-depth interviewing, storyline graphs and photo elicitation (Harper, 2002; Sandelowski, 1999). Qualitative data collection methods provide a comprehensive examination of the meaning that the constructs hold for participants (Mullings & Schulz, 2006). The methods also engage participants in describing their own strengths and vulnerabilities in everyday life and illuminate the implications of social and economic contexts for health.

In-depth qualitative interviews are well suited to an intersectional approach because of their ability to provide rich descriptions of complex phenomena and their meanings and relationships to one another (Mullings & Schulz, 2006). Storyline graphs and photo elicitation will accompany the interviews. Storyline graphs are a tool in which the participants are asked to reflect on and select key health-related events such as their HIV diagnosis and pregnancy(ies) and they are then plotted on a time line (Sandelowski, 1999). The graphs are used to elicit information about the health experiences and help illuminate their temporal relationships to one another as well as other key life events participants deem relevant (Sandelowski, 1999). Photo elicitation uses photography as a data elicitation technique (Harper, 2002) and in this study the participants conceive of, take and describe photos they believe best represent the social and economic complexities affecting their health. The photos are then used to stimulate dialogue about the social and economic complexities of the mother’s lives. Together, in-depth
interviews, storyline graphs and participant-initiated photography will provide the
detail needed to understand the complex intersection of social determinants of health for
these mothers.

1.4 Purpose Statement and Aims

The overall purpose of this dissertation is to develop knowledge on the social
determinants of health for African American HIV-infected mothers by exploring their
mutually constituted social identity at the intersection of gender-, race- and class –
inequality; HIV-related stigma; and motherhood. This purpose will be accomplished
through five overall aims, with each chapter representing one aim.

1.4.1 Chapter 1 Aim

Introduce the problem and significance and intersectional approach

1.4.2 Chapter 2 Aims

1.4.2.1 Chapter 2 Aim 1

Describe and analyze intersectionality as a conceptual framework and means of
understanding and addressing health and health care inequities (Caiola, Docherty, Relf,
& Barroso, 2014)

1.4.2.2 Chapter 2 Aim 2

Apply the intersectional approach to the study of the social determinants of
health for African American mothers living with HIV and through this application
explore the utility of an intersectional approach to generate knowledge in nursing

(Caiola et al., 2014)

1.4.2.3 Chapter 2 Aim 3

Discuss some of the potential methodological implications of using an intersectional framework in research (Caiola et al., 2014)

1.4.3 Chapter 3 Aim

Explore the methodological issues and ethical challenges of using photographs as a data elicitation technique with a highly stigmatized and vulnerable group of women

1.4.4 Chapter 4 Aims

1.4.4.1 Chapter 4 Aim 1

Describe the specific social location of African American HIV-infected mothers and their mutually constituted social identity at the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood

1.4.4.2 Chapter 4 Aim 2

Explore the ways in which the unique social identity of African American HIV-infected mothers influences their health-related experiences

1.4.5 Chapter 5 Aim

Synthesize and analyze the social determinants of health for African American mothers living with HIV and any new knowledge about how those social determinants
intersect to create a specific social location and subsequent health outcomes for these women.

The proposed dissertation will help to generate hypotheses about how the described intersection of these social determinants operate to shape health behaviors and produce health outcomes for African American mothers living with HIV and will identify aspects of the problem that can be measured, are amenable to change, and thus can be meaningfully addressed by intervention (Fleury & Sidani, 2012). Additionally, the feasibility of using photo elicitation in highly stigmatized group will be examined. In conclusion, the knowledge generated from this dissertation is significant because it will inform future research aimed at developing health interventions for African American mothers living with HIV to improve their health outcomes through enhanced social environments and an improved response to the social and economic complexities of their lives (Hankivsky, 2012).
2. Using an Intersectional Approach to Study the Impact of Social Determinants of Health for African American Mothers Living with HIV

(Caiola et al., 2014)

2.1 Abstract

Heightened awareness of the social determinants of health by health scientists and clinicians has failed to translate into significant progress in the amelioration of those social determinants contributing to health inequities. The purpose of this article is to broaden the discussion about conceptual approaches nurse scientists can use to address health and health inequities. We will apply an intersectional approach to the study of the social determinants of health for African American mothers living with human immunodeficiency virus and through this explore the utility of an intersectional approach to generate knowledge in nursing.

2.2 Introduction

This article outlines an approach to conceptualizing social determinants of health and their role in producing health inequities. Health scientists and clinicians are increasingly recognizing that health care systems and the conditions in which people are born, grow up, live, work, and age—collectively known as the social determinants—profoundly influence the health of individuals and subsequently impact the health of
populations at large (Adimora & Auerbach, 2010; CSDH, 2008; Hankivsky, 2012). Since
the turn of the 21st century, a number of important publications illuminate the
significant role social determinants play in producing health inequities. For instance, in
2003, the Institute of Medicine produced the first comprehensive report demonstrating
that racial and ethnic minorities have less access to quality health care (Smedley, Stith, &
Nelson, 2003). In 2008, the World Health Organization announced a new global agenda
for health equity, clearly asserting and substantiating that the social determinants of
health, fashioned by the distribution of power and material resources, function to
produce many avoidable health inequities (Adimora & Auerbach, 2010; CSDH, 2008). In
2010, the Centers for Disease Control and Prevention produced a white paper calling for
new approaches, beyond individual interventions, to reduce health inequities in human
immunodeficiency virus (HIV), viral hepatitis, sexually transmitted infections (STIs),
and tuberculosis in the United States (CDCP, 2010a). Within country and between-
country analyses show that social determinants such as gender, occupation, income, and
race/ethnicity can radically influence health outcomes to create hierarchies of health and
illness (CDCP, 2010a; CSDH, 2008). In conjunction with these publications, presidential
communications and working groups (Obama, 2012), a national HIV/AIDS health
strategy (National HIV/AIDS Strategy for the United States, 2010), legislation such as the
Patient Protection and Affordable Care Act, and federally funded research efforts to
promote the investigation of multifactorial, nonbiological factors of health disparities (Committee on the Review and Assessment of the NIH's Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, 2006) have heightened awareness of the role of social determinants in producing health outcomes (U. A. Kelly, 2009; Weber, 2006).

Despite increased efforts and heightened awareness of social determinants of health, little to no progress has been made in the amelioration of those social determinants contributing to health inequities. In fact, a review of Healthy People 2010 reveals that during the decade between 2000 and 2010, the disparity gaps for many of leading health indicators by race and ethnicity have actually worsened, rather than improved; a disappointing 70% of the objectives saw no change in disparity (Sondik, Huang, Klein, & Satcher, 2010). We argue, along with a growing number of health scientists, that reliance on traditional biomedical research paradigms, which reflect a positivist epistemology, serves to perpetuate these trends by failing to adequately consider the social and economic context of health, preserving the hegemony of the Euro- and androcentric perspectives often driving research, and ignoring the unequal power distributions contributing to health inequities (Hankivsky, 2012; U. A. Kelly, 2009; Weber, 2006).

In contrast to traditional biomedical research paradigms, many feminist and
sociology scholars focus on the influence of unequal power distribution and social and economic situations in positioning people in the social world (Crenshaw, 1989; Guidroz & Berger, 2009; Hill Collins, 1994, 2000). Over the past 3 decades, these scholars have developed a conceptual framework called intersectionality or an intersectional approach when applied in research (McCall, 2009), aimed at understanding these complexities (Hankivsky, 2012; McCall, 2009; Weber, 2006). Research endeavors using the intersectional framework generally manifest as multidisciplinary scholarship examining how the hierarchies of race, gender, and class mutually create structures of oppression and meaning (McCall, 2009). More recently, scholars began using intersectional approaches to examine the complex configurations of social determinants of health and how those social constructs interact to produce health inequities (Hankivsky, 2012; U. A. Kelly, 2009; Weber, 2006). Nevertheless, the utilization of intersectionality to aid nurse scientists in knowledge development and inform nursing practice regarding issues of social injustice and health inequities is only just evolving (U. A. Kelly, 2009).

The purpose of this article is thus 3-fold. First, we will describe and analyze intersectionality as a conceptual framework and a means of understanding and addressing health and health care inequities. Second, we will apply the intersectional approach to the study of the social determinants of health for African American mothers living with HIV and through this application explore the utility of an intersectional
approach to generate knowledge in nursing. Finally, we will discuss some potential methodological implications of using an intersectional framework in research.

2.3 An Intersectional Approach: Conceptualizing Health and Health Care Inequities

Beginning roughly in the late 1980s and early 1990s, intersectionality developed through both scholarly endeavors and activist engagement (Guidroz & Berger, 2009). Kimberle Crenshaw, a lawyer and African American feminist scholar, is most frequently cited as coining the term “intersectionality” in her early scholarly work (Crenshaw, 1989, 1991; McCall, 2009), which was inspired by her activism in Harvard Law School’s faculty integration of both women and people of color (Guidroz & Berger, 2009). Crenshaw emphasizes that intersectionality is not merely a multiplying of identity categories such as gender and race, rather, it is meant to provide a means of analysis for how particular identities and conditions are located within structures of power (Guidroz & Berger, 2009). Patricia Hill Collins, African American sociologist and feminist scholar, began publishing extensively on intersectionality in 1990 with her work entitled Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment (Hill Collins, 2000). Collins critiques the essentialism of feminist scholarship of that time and suggests that social theory that fails to acknowledge social context produces theories that appear to be universal but in reality reflect only the thought-models of the scholars located in their
specific social context (Hill Collins, 1994). Intersectionality is a way of understanding social location in terms of the way systems of race, social class, and gender overlap with no one social category taking primacy (Hankivsky, 2012).

2.4 Orientation and Purpose of Intersectionality

Said by some scholars to be a transformative paradigm, intersectionality’s philosophical underpinnings are largely rooted in critical theory and feminism, and no single theorist or discipline can be credited with its development (Guidroz & Berger, 2009; McCall, 2009). A core epistemological assumption of intersectionality is that knowledge development is from the perspective of the oppressed, not the dominant social group (U. A. Kelly, 2009). Intersectional scholarship was developed from the unique position of women of color, with the purposes of seeking social justice and framing social inequities as products of differences such as race, class, and gender (U. A. Kelly, 2009; Weber, 2006). In other words, intersectionality is both an explanatory conceptual framework and an effort to address social inequality on the basis of intersecting social constructions (such as race, class, and gender) manifested at both the individual and population levels (Mullings & Schulz, 2006). Intersectional scholars consider the social constructions of gender, race, and class to be unequal social relationships between groups of people, rather than biological or genetic attributes of individuals, and they are concerned with how those relationships act as social
determinants of health disparities (Mullings & Schulz, 2006).

2.5 Central Theoretical Tenets of Intersectionality

We recognize that there are a multitude of conceptualizations of intersectionality and contradictions in the literature about intersectionality (Hankivsky, 2012; U. A. Kelly, 2009), it is simultaneously characterized as a paradigmatic view, a theoretical framework, and a methodological approach (McCall, 2005, 2009). However, some basic theoretical tenets characterize much of the literature on intersectionality. Weber’s work identifying the central theoretical tenets of intersectionality serves as a useful framework of the approach’s central constructs: contextually specific social constructions, multilevel power relations, and simultaneity (Weber, 2006).

2.5.1 Contextually specific social constructions

Intersectionality describes broad social categories such as race, gender, and class, along with more specific social categories such as motherhood, as socially constructed phenomena that are fluid, flexible, and contextually grounded in history and geographical location (Hankivsky, 2012; Weber, 2006). For example, social constructions of race are not based on the assumption that discrete, biological races exist, rather, they are concerned with how race is constructed by historical conditions such as slavery and segregation and leads to inequity based on hierarchies and systems of oppression (Mullings & Schulz, 2006).
Social roles such as motherhood are also considered social constructions in intersectionality. For example, within an intersectional framework, motherhood is not assumed to be a universal phenomenon with a single, objective definition of mothering. Rather, mothering is thought of as a relationship in which a person’s action to nurture and care for another is based in a historical and cultural context (Hill Collins, 1994; Nakano Glenn, 1994). Collins’ theorizing about motherhood explicitly challenges universalism, acknowledges inherent diversity in motherhood, and suggests a shift to a concept that accommodates the diversity of race, ethnicity, and social class (Hill Collins, 1994). Her work on motherhood is firmly grounded in an intersectional approach—an approach she is credited with helping to shape (McCall, 2009). From an intersectional approach, there is no one meaning of motherhood, manhood, womanhood, or the like; they are deeply embedded in the social context from which they arise (Hill Collins, 1994; Mullings & Schulz, 2006).

### 2.5.2 Multilevel power relations

The exploration of social relationships marked by a power differential—in which one group is subordinate and another is dominant—as well as how those relationships persist is a central focus of intersectionality (Weber, 2006). Social relationships are interactions between the people assigned to socially constructed categories of difference noted previously such as race, gender, and class; the persistence of power in such
relationships is fashioned by the dominant group’s access to greater material and social resources (Weber, 2006). As power relationships persist and hierarchies are perpetuated, the dominant social groups become the standard from which all group comparisons are made and subordinate social groups are subsequently marginalized (Weber, 2006).

Macrolevel power differentials manifest structurally in the form of policies, rules, or laws benefiting only certain groups, while microlevel power differentials present in individual relationships in which one individual exerts power over another (Weber, 2006).

2.5.3 Simultaneity

Socially constructed differences in gender, race, and class do not simply intersect in an intersectional approach as an inequity that is additive or multiplicative (Mullings & Schulz, 2006). Rather, the constructs exist simultaneously and vary as a function of one another depending on the particular gender, race, and class to which an individual belongs (Mullings & Schulz, 2006). The ability of the constructs to vary as a function of one another is described as “mutually constituted,” creating a specific social location for individuals (Hill Collins, 1998; McCall, 2009; Weber, 2006). An individual’s social location based on mutually constituted social inequities is an important concept in intersectionality and is often best explicated by example. Using health as an example, the intersection of social determinants of health for an African American (race) mother
(gender) living in poverty (class) and with HIV may function quite differently than that of an African American (race) father (gender) living in poverty (class) and with HIV. That is, race and class are gendered and may operate to produce different health outcomes (Mullings & Schulz, 2006) as well as a unique social location for those individuals. Indeed, the combinations are innumerable depending on the social determinants of concern, as race and gender could just as conceivably be “classed” or gender and class could be “raced” (Mullings & Schulz, 2006). Finally, but very importantly, intersectionality challenges the idea of gender as the primary dimension of inequity; rather, it asserts that multiple dimensions can and do shape social inequality (Hankivsky, 2012).

### 2.6 Analysis of Intersectionality

We assert that the strengths of intersectionality as an approach for investigating health disparities are clear, namely, it provides insights into the nature of social inequality, social determinants of health, and power structure. Indeed, it provides some clear advantages over the biomedical paradigm. First, acknowledgement of social constructions of difference requires the researcher(s) to develop a specific awareness of the community of interest, including nuances of community strengths, weaknesses, historical context, political context, and more (Weber, 2006). This awareness, long advocated for by feminist and critical scholars, fosters researcher and participant
engagement, self-reflection, and involvement (Weber, 2006) such that participants are no longer subjects to the research process but involved at a level in which a process of conscientisation may occur (Ledwith, 2012). Conscientisation, a concept originally developed by Paulo Freire, is a process of consciousness raising and critical awareness through practice and participation (Ledwith, 2012). Such participant involvement and conscientisation is in itself a community intervention and may lead to more appropriate community-based interventions where biomedical approaches have failed.

Second, the acknowledgement of power relations in intersectionality has 3 important consequences. One, as discussed earlier, the intentional privileging of the perspectives of groups traditionally subordinated means that dominant groups are no longer considered the standard from which all group comparisons are made and moves health research away from a traditional Euro- and androcentric perspective (U. A. Kelly, 2009; Weber, 2006). Two, comprehensive examination of power structures leaves room for the study of privilege and how the process of whiteness is central to producing health inequities (Frankenberg, 1997; Hankivsky, 2012). Whiteness is not only a social location of structural privilege by white people but also the unmarked and seemingly transparent practices and discourse that perpetuate racial domination and reproduce social inequality in society (Frankenberg, 1997). A worthy endeavor and example of research investigating the role of whiteness might be using an intersectional approach to
examine the discourse between elite, white politicians who are largely responsible for brokering health policy in the United States. Three, exploration and disclosure of power differentials at the macrolevel requires health scientists to consider health interventions aimed at balancing power at the structural or institutional level rather than the microlevel interventions, such as individual behavior change, traditionally targeted by biomedical research (Weber, 2006).

Third, by stressing simultaneity, intersectionality moves beyond the single-axis analysis centered on dichotomies such a man/woman, African American/white, and wealthy/poor and provides a means for multiaxis analyses in which heterogeneity is implicit (Hankivsky, 2012) and no social group is considered homogeneous (U. A. Kelly, 2009). In doing so, intersectionality creates a more empirically sound model of diversity and challenges the “binary thinking which tends to place certain groups in opposition to one another” in the biomedical paradigm (Hankivsky, 2012, p. 1713).

We do acknowledge that the methodological complexities of executing an intersectional approach can be daunting and might be considered a potential weakness of the framework (McCall, 2005, 2009). These complexities have likely evolved because intersectionality grew out of multiple disciplines, and the methodological boundaries of various disciplines can vary significantly (Weber, 2006). We suggest the lack of clarity as to the nature of intersectionality as a paradigm or theory, and the methodological
complexities associated with intersectionality are not weaknesses but opportunities for creating new ways of knowing. In the following section, we will address some of these issues through application of an intersectional approach to research involving African American mothers living with HIV and suggest a model of the theoretical relationships within the framework.

2.7 Exemplar: The Practical Application of an Intersectional Approach

As a means of evaluating intersectionality, we will discuss the applicability and limitations of the conceptual framework for investigating the health inequities and social determinants of African American mothers living with HIV. To begin, it is important to explain the rationale for the population and disease process chosen, as the choices have distinct methodological implications in an intersectional framework.

2.7.1 Population and disease process rationale

The rationale for choosing one socially constructed group (African American women) at the intersection of multiple social identities (female, African American, mothers, living in poverty) is driven by the intersectional framework itself. Managing the complexity of multiple categories simultaneously has proven to be challenging for intersectional scholars (McCall, 2005). Efforts to manage complexity and still produce findings led to 3 primary methodological approaches—anticategorical, intracategorical,
and intercategorical (McCall, 2005). These approaches fall on a continuum, with anticategorical and intercategorical landing on the extremes of the spectrum (McCall, 2005). Simply stated, anticategorical approaches deny any fixed categories, and intercategorical approaches, similar to traditional biomedical approaches, analyze multiple social groups within and across categories (U. A. Kelly, 2009; McCall, 2005).

The approach chosen for this discussion, intracategorical, focuses on one social group at the intersection of multiple social identities so that within-group differences and larger social structures influencing their lives can be explicated (U. A. Kelly, 2009; McCall, 2005).

The rationale for choosing African American mothers living with HIV is 2-fold. One, this choice is in keeping with the premise that intersectional approaches focus on knowledge development via nondominant, minority, and frequently marginalized groups. Two, this choice is based on magnitude of disease burden and disparity in health outcomes. Indeed, disparities in the health outcomes for African American mothers living with HIV are clear across racial, gender, and socioeconomic groups. Women now represent 25% of all HIV infections in the United States (CDCP, 2014a). African American women are 20 times more likely than white women to be newly infected with HIV (CDCP, 2014a), and once infected, they are likely to die from AIDS earlier than their white counterparts (CDCP, 2007b). Moreover, African American
women are disproportionately poorer than other subpopulations in the United States (Elmelech & Lu, 2004) and at least twice as likely as white women to be living in poverty, a significant precipitating factor for HIV infection (CDCP, 2010b). Being a mother adds an extra layer of complexity to the lives of women living with HIV. Studies show that the primary goals of mothers living with HIV are to protect their children from HIV infection and HIV-related stigma (Sandelowski & Barroso, 2003); these mothers describe higher levels of stress than nonmothers as they manage their own needs and the needs of their children in circumstances such as poverty (Jones et al., 2003). Human immunodeficiency virus–related stigma brings poorer mental and physical health outcomes across a broad range of demographic profiles (Logie & Gadalla, 2009). If vulnerability is defined as the “susceptibility to poor health” (Shi & Stevens, 2010, p. 2), then the vulnerability of African American mothers living with HIV functions at the intersection of gender (Higgins et al., 2010), race (Smedley, 2012), class (CDCP, 2010b), HIV-related stigma (Logie & Gadalla, 2009), and motherhood (Sandelowski & Barroso, 2003), and necessitates multidimensional and transdisciplinary approaches to address the complex social and economic conditions of these mother’s lives, collectively known as social determinants of health.

2.7.2 Intersectional Approach for Research Involving African American Mothers Living with HIV

The intersectional approach is based on a model titled Motherhood and HIV: An
Intersectional Approach. In this model (Figure 2), informed by the work of Shi and Steven (2010), the concept of vulnerability, defined as a “susceptibility to poor health,” is at the center (p.2). The model represents the intersection of specific factors as mutually constituted (Hankivsky, 2012; Hill Collins, 1998; Mullings & Schulz, 2006; Weber, 2006) vulnerability in which these factors jointly determine health status and access to quality health care.

![Motherhood and HIV: An Intersectional Approach](image)

**Figure 2: Motherhood and HIV: An Intersectional Approach**

To illustrate the conceptual relationships in the intersectional model (Figure 2), a mother living with HIV is shown standing at a large traffic intersection with her children in tow. Her challenge is to cross the intersection safely, protecting both herself and her
children. In the model, (1) the social determinants of health (represented by roads) intersect to create a mutually constituted vulnerability; (2) the larger the intersection (ie, the more vulnerabilities), the more difficult the mother’s task of managing her condition and accessing quality health care, leading to a greater likelihood of poor health outcomes; (3) gender, race, and class are socially constructed categories involving sometimes unequal relationships between groups of people, rather than biological or genetic attributes of individuals (Mullings & Schulz, 2006); (4) certain factors (represented by bridges) can positively influence the ability of a mother living with HIV to navigate the intersection and her subsequent health outcomes; and (5) the health outcomes of the children are at least partially dependent on the health outcomes of the mother and her ability to navigate the intersection. Definitions of the concepts used in the model, along with rationale for their inclusion, follow.

2.7.2.1 Gender/gender inequality

Gender is a socially constructed category with differences in how it is enacted and arranged hierarchically in society (Mullings & Schulz, 2006). Gender inequality based on hierarchical structures can lead to differences in health outcomes between men and women due to distinctive social roles and expectations (Jackson & Williams, 2006). Gender inequality (Zierler & Krieger, 1997) and gender-based violence (Maman, Campbell, Sweat, & Gielen, 2000) increase the risk of HIV infection, and increased
violence among women already living with HIV leads to poorer health outcomes (Maman et al., 2000).

2.7.2.2 Race/race inequality or racism

Race is a socially constructed group of categories that can lead to inequity based on hierarchies and systems of oppression (Mullings & Schulz, 2006). Health scientists have found that the social impact of race on daily life experiences, not innate biological differences or poverty, actually mediates differences in race-associated health outcomes (Geronimus, Hicken, Keene, & Bound, 2006). High levels of self-reported experiences of racism have been associated with numerous poor health outcomes, from cardiovascular disease to certain forms of cancer (Smedley, 2012).

2.7.2.3 Class/class inequality

Class is a relative position along a socioeconomic gradient and it has been associated with poor health through material deprivation or “the lack of material resources that enable the protection or promotion of health” (Shi & Stevens, 2010, p. 66). Epidemiological studies have found an association between HIV infection risk and poverty (CDCP, 2010b) and have shown that socioeconomic status is a major determinant of high morbidity among nonwhite women living with HIV in the Southern region of the United States (Meditz et al., 2011).
2.7.2.4 HIV-related stigma

In his landmark work, Erving Goffman (1963) defined stigma as both a discrediting attribute of an individual and a social process in which the discredited individual is rejected by society (Goffman, 1963). A recent meta-analysis concluded that high HIV-related stigma is correlated with poor physical outcomes such as AIDS symptoms; poor mental health outcomes such as depression, anxiety, and psychological distress; and low social support (Logie & Gadalla, 2009). In addition, HIV-related stigma has been identified as a significant barrier to initiation of HIV care (Pollini, Blanco, Crump, & Zuniga, 2011) and associated with greater gaps in medical care as measured by days, antiretroviral therapy nonadherence, low CD4 cell counts (< 200 cells/mm$^3$), and higher chronic illness comorbidity (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013).

2.7.2.5 Motherhood

Nakano Glenn (1994) reframed “mother” from a biological construct into “mother” as a social construct, by defining mothering as a relationship in which a person’s actions to nurture and care for another are based in a historical and cultural context (Nakano Glenn, 1994). Research exploring the experiences of women living with HIV has revealed that motherhood creates added challenges and higher levels of stress for women who must manage their own health care needs while simultaneously acting
as caregivers to their children (Jones et al., 2003). Mothers living with HIV also experience role conflicts as they attempt to carry out the daily activities of motherhood while experiencing profound fatigue and other physical limitations imposed by their disease (Murphy, Johnston Roberts, et al., 2011). Finally, mothers living with HIV desire to protect their children from HIV-related stigma and experience stress in regard to disclosure of their HIV status to their children, significant others, and other family members, fearing that disclosure will make their children vulnerable to stigma (Sandelowski & Barroso, 2003). As such, these mothers also have concerns about the care of their children in case they become ill and die, and paradoxically they cite motherhood and the desire to protect their children as a source of strength and a reason to live despite their infection (Sandelowski & Barroso, 2003). The evidence as to whether motherhood plays a positive (Sandelowski & Barroso, 2003) or negative (Jones et al., 2003; Murphy, Johnston Roberts, et al., 2011; Sandelowski & Barroso, 2003) role in health outcomes for mothers living with HIV is conflicting; therefore, motherhood could be explored as both an axis of vulnerability and as a potential strength in an intersectional framework.

We argue that an intersectional approach is highly applicable to research on the impact of social determinants of health for African American mothers living with HIV and a number of other populations experiencing disparate health outcomes. Modifiable
health status in chronic illnesses such as HIV is largely determined by environmental, social, and behavioral factors (Thygeson, 2013); in 2010, as part of the Patient Protection and Affordable Care Act, Congress authorized funding of the Patient-Centered Outcomes Research Trust Fund aimed at producing information from research that is guided by patients and other stakeholders to illuminate these factors. As the United States moves toward more patient-centered care, understanding the role of social determinants in patients’ health will be central to the design of interventions that will help ameliorate those social determinants when they do not promote health.

Unlike a general intersectional approach, our model emphasizes access to quality health care, health outcomes, and potential health promoting social determinants (Shi & Stevens, 2010). It encourages understanding potential pathways and relationships social determinants have with health access, health quality, and health outcomes both at the individual and population levels. In addition, we argue that it is critical to examine health promoting (or positive) social determinants of health that will move research from a deficit model to identify and capitalize on those patient and community attributes that enhance health (Thygeson, 2013).

Using an intersectional approach to investigate disparate health outcomes in HIV and other chronic illnesses could potentially address important questions such as the following: What mutually constituted social determinants contribute to the prevalence
of a specified disease? How are those social determinants related and how are they embedded in power structures for specific diseases or populations? What are some of the health-promoting social determinants, such as motherhood, that can enhance a patient’s ability to self-manage a disease process? Can structural interventions and health policies be developed to improve the health disparity found in people with specific disease processes across gender, race, and class groups?

2.8 Implications of Using an Intersectional Approach

The methodological implications of using an intersectional approach, such as the one we have proposed previously, are vast, and entire texts have been devoted primarily to this topic (McCall, 2009; Mullings & Schulz, 2006). Intersectional scholars have asserted that intersectional approaches tend to be less amenable to traditional biomedical, variable-oriented, or disaggregating methodologies such as multivariate, predictive models (Mullings & Schulz, 2006). Such methods seek to explain the relationship between independent, discrete variables but they do not explain why those relationships occur or illuminate their social and context-dependent constructions or the power structures within those relationships (Mullings & Schulz, 2006). Others have suggested that intersectional approaches have a closer alignment with or affinity with traditional qualitative methodological approaches such as ethnography or case study accounts (Mullings & Schulz, 2006). Kelly (2009), a nurse scientist, moves the
conversation forward for nursing by discrediting a strictly dichotomous intersectional versus biomedical paradigm and qualitative versus quantitative view and suggests that “the integration of feminist intersectionality and biomedical paradigm in research occurs in the selection of the research problems, design, and methods, as well as in the operationalization of the assumptions of each paradigm throughout the research process (p. E46). In other words, retreating to comparisons of the biomedical versus intersectional paradigms and their traditional affiliations with quantitative versus qualitative methods, respectively, simply reinforces a binary form of thinking that only 1 philosophical approach can address the complexity of health inequities and fails to acknowledge that philosophical or theoretical approaches are in no way tied to specific methodologies (Sandelowski, 2014). Integration of the intersectional and biomedical paradigm for the purpose of addressing health inequities will require an orientation toward the data, no matter the methodology with which these are collected, such that questions related to socially constructed categories of difference, power differentials, and mutually constituted social identities are considered. Scholars using the intersectional approach also have a long tradition of combining scholarship and activism in the pursuit of social justice; therefore, community-based participatory research is uniquely suited to intersectional approach because of its emphasis on participant-researcher collaboration and community engagement (U. A. Kelly, 2009; McCall, 2009).
In addition, intersectional approaches may be served best by transdisciplinary groups of scholars engaging in collaborative research efforts. As McCall (2009) asserts, intersectional approaches cross disciplinary borders and such a “border-crossing concept suggests an interdisciplinary rigor that helps challenge traditional ways of framing research inquiries, questions and methods (p.7).

Finally, this approach is particularly powerful for the design and implementation of interventions. Structural interventions, which focus on changing the “environment or context within which people act for the purpose of influencing individual health behaviors” (D. A. Cohen, Wu, & Farley, 2006, p. S46) attempt to target the social determinants associated with negative population health outcomes (Adimora & Auerbach, 2010). Social determinants include not only socially constructed categories such as race, gender, and class (Mullings & Schulz, 2006) but also built environment such as actual neighborhoods and community spaces or trusted and reciprocal social networks (Renalds, Smith, & Hale, 2010). By illuminating the social determinants negatively and positively impacting health and how those social determinants interact, we can assess which, if any, of those structural influences may be amenable to intervention via health policy and advocacy. As related to our example of African American mothers living with HIV, inquiry framed with an intersectional approach may produce evidence substantiating the nuances of how macrolevel power differentials
create their disparate health outcomes. For example, does one social determinant such as
class inequality consistently trump other determinants such as gender or race in
producing negative health outcomes? Can the intersection of the racism, classism,
gender inequality, and stigma be mitigated by motherhood? How does whiteness
operate to shape the health experiences of these mothers? Research using an
intersectional approach and our proposed model can unveil such nuances. The evidence
could then be used to advocate for structural interventions aimed at altering imbalances
of power, such as the provision of microfinancing programs to reduce economic
inequality (Adimora & Auerbach, 2010) or antiracist education to challenge and change
the unmarked white privilege of the US health care system (Schroeder & DiAngelo,
2010).

Process interventions are nested within structures and aimed at impacting
individual health and health behaviors through specific health care processes such as
evidence-based care, behavior change management, and the patient-provider
relationship (Safford, Allison, & Kiefe, 2007; Sidani & Braden, 2011; Thygeson, 2013). For
example, exploring the ways in which the unique social identity of African American
mothers living with HIV influences their health-related experiences and creating
empirically driven typologies of vulnerability, researchers have a potential means for
assessing vulnerability that may be clinically relevant for clinicians (Safford et al., 2007).
Being able to adequately assess vulnerability gives clinicians a greater understanding of social forces influencing a patient’s health care decisions and will allow for a greater congruence or shared understanding between the provider and the patient regarding “realistically attainable health care goals” (Safford et al., 2007, p. 384). Such an assessment literally gives the provider a sense of what it is like for the mother, as she stands in the middle of the intersection of social determinants and the potential “trade-off” decisions she must make regarding her health care, such as whether to buy her medications or clothing for her child (Safford et al., 2007). This kind of evidence could be used to develop HIV-specific, evidence-based guidelines for mothers that (1) consider how a mother’s assessed vulnerability changes certain health care recommendations, (2) provide a patient-provider decision-making tool for trade-off decisions, and (3) suggest ways providers can adapt their health practice in caring for mothers living with HIV (Safford et al., 2007; Thygeson, 2013). Few guidelines such as these exist, but an excellent example is the guidelines provided by the Health Care for Homeless Clinicians Network called Adapting Your Practice: Treatment & Recommendations for Homeless Patients With HIV/AIDS (“Adapting Your Practice: Treatment & Recommendations for the Care of Homeless Patients with HIV/AIDS,” 2008).

2.9 Conclusion

To date, the acknowledgement of the role of social determinants in producing
health inequities by the scientific community has failed to translate into significant progress toward interventions that ameliorate disparate health outcomes among populations. As health care scientists, we urgently need to expand our understanding of health inequities and the means with which we investigate them. An intersectional approach offers a complexity of inquiry matching the complexity of social forces shaping those inequities. Our model of Motherhood and HIV: An Intersectional Approach, while specific to African American mothers living with HIV, can be modified to reflect the social determinants of health relevant to a multitude of other populations and offers a framework for this future work.
3. One Size Does Not Fit All: Tailoring a Visual Methods Protocol for Mothers Living with HV in the Deep South

Visual methods in which images are used for data elicitation or as the data themselves are increasingly being adopted and tailored for health research (Cox et al., 2014). Photo elicitation, a specific example of such visual methods, is a qualitative interviewing technique in which the researcher utilizes photographs to acquire information in the research interview (Bugos et al., 2014; Harper, 2002). The photographs may be taken by the researcher, the study participant, or be artifacts (Harper, 2002). Photo elicitation is an essential element of the community-based participatory action research methodology called Photovoice and the terms are frequently used interchangeably; however, they are distinguished by their intent (Bugos et al., 2014; Padgett, Smith, Derejko, Henwood, & Tiderington, 2013). Photovoice, a community-based participatory and action-oriented research method grounded in feminist and critical theory, is intended to promote dialogue regarding community strengths and concerns through the discussion of photographs (Wang & Burris, 1997). Both photo elicitation and Photovoice offer elements of participant control and engagement in the research process, assist in fostering dialogue, create an alternative or adjunct to verbal methods of data elicitation and help to make participants active members in improving their own health (Guillemin & Drew, 2010; Harper, 2002; Padgett et al., 2013; Wang,
The use of Photovoice and photo elicitation with persons living with HIV is steadily growing and has been shown to be effective in detailing the realities of living with HIV, stimulating community dialogue, and successfully maintaining participant confidentiality (Gosselink & Myllykangas, 2007; Hergenrather, Rhodes, & Clark, 2006; Mignone et al., 2014; Rhodes, Hergenrather, Wilkin, & Jolly, 2008; Teti, French, Bonney, & Lightfoot, 2015; Teti, Murray, Johnson, & Binson, 2012; Teti, Pichon, Kabel, Farnan, & Binson, 2013). To our knowledge, however, these visual methods have not been used with mothers living with HIV, and using a methodology in which visual images are created and made public can pose ethical challenges unique to each population and setting (Bugos et al., 2014; Cox et al., 2014; Harper, 2002; Teti et al., 2012). Who you are and where you reside can be of particular consequence for participants of research studies utilizing visual methods.

3.1 Vulnerability: Why the “Who and Where” Matters

The susceptibility to poor health outcomes for Black/African American mothers living with HIV in the Deep South region of the United States functions at the intersection of gender, race, class, motherhood, geographical location and HIV-related stigma, necessitating multidimensional approaches such as photo elicitation to study the complex social and economic conditions of their lives. However, visual images used
with this population generate unique methodological issues and ethical challenges. The ethical implications of using visual images as research data must be carefully considered, as the methodology itself has potential to expose information about research participants’ lives, their children’s lives and their HIV serostatus (Bugos et al., 2014; Cox et al., 2014; Teti et al., 2012).

The designation of African American mothers living with HIV as a vulnerable population in health research is based on specific attributes such as predisposing characteristics (i.e., racial/ethnic minorities and gender), enabling factors (i.e., potentially uninsured and low socioeconomic status) and health need factors (i.e., chronic illness) increasing one’s susceptibility to poor health outcomes (Shi & Stevens, 2010). Women now represent almost one quarter of all the HIV infections in the United States and the vast majority of new infections are from heterosexual contact (CDCP, 2014a). African American women are disproportionately affected by HIV, twenty times more likely than White women to be newly infected with HIV (CDCP, 2015), and likely to die earlier from AIDS than their White counterparts (Losina et al., 2009). Women of color are also overrepresented among poor people in the United States (U.S. Census Bureau, 2012), and while the relation between poverty and HIV infection is nuanced and not well understood, poverty is a significant determinant of HIV infection (CDCP, 2010b).
Motherhood is of great consequence to women living with HIV and can introduce further aspects of vulnerability, such as HIV-related stigma. A meta-synthesis of studies demonstrated that mothers living with HIV prioritize protecting their children from HIV infection and HIV-related stigma (Sandelowski & Barroso, 2003). The negative consequences of HIV-related stigma on mental and physical health outcomes are largely indiscriminate of specific demographic profiles (Logie & Gadalla, 2009), but mothers bear the additional burden of attempting to protect their children from HIV-related stigma. Disclosure of their HIV status to their children, significant others and other family members has been shown to be particularly stressful because mothers fear that disclosure will make their children vulnerable to stigma (Sandelowski & Barroso, 2003).

Residing in one of the nine states in the southern United States designated as a “target state” is also of particular consequence for African American mothers living with HIV. Analyses using the data from the Center for Disease Control and Prevention’s (CDCP) National HIV Surveillance System reveal that higher proportions of young African American women residing in these states are diagnosed with HIV than in other regions of the country; these states have the highest death rates among persons living with HIV; and factors contributing to these disparities include overall poor health status, high poverty rates, and a cultural conservatism fostering HIV-related stigma in the
region (Human Rights Watch, 2010; Reif et al., 2014; Reif, Whetten, Wilson, & Gong, 2011).

The overall purpose of this paper, therefore, is to explore the methodological issues and ethical challenges of using photographs as a data elicitation technique with a highly stigmatized and vulnerable social group of women. To achieve this purpose we draw from the preliminary findings of a study to: (a) discuss the feasibility of photo elicitation as a data collection technique; (b) highlight the utility of photographs as a data elicitation technique used in conjunction with in-depth qualitative interviewing; (b) examine specific ethical challenges encountered and how we then tailored our research protocol for the study; and (c) suggest best practices for using visual methods with a vulnerable population.

3.2 The Study

The overall aim of the study was to describe the social determinants of health for African American mothers living with HIV by exploring their social identity and subsequent health experiences at the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood. We chose to use photo elicitation as one of the data collection methods and opted to use it as a data elicitation technique with individual mothers rather than the Photovoice group approach. This decision was made in an effort to draw on the strengths inherent to both methods, while hopefully
minimizing some of the potential risks of a group exercise. In particular, we were concerned about risks associated with HIV status disclosure and HIV-related stigma. We wanted to respect mothers’ concerns for potential unintentional HIV status disclosure and the stigma their children may experience from such disclosure (Sandelowski & Barroso, 2003). Additionally, we wanted to be mindful of the study locale, a relatively socially conservative region of the United States in which HIV-related stigma continues to play a key role in health outcomes, particularly among those living in the African American community (Human Rights Watch, 2010). Finally, we chose to have the study participants conceive of, take and describe the study photographs in order to provide the highest level of participant control and engagement in the research process.

3.2.1 Setting, Sample and Ethical Review

The setting for this study was a semi-urban area of one of the Deep South “target states” of the United States identified in the previously mentioned report from the Southern HIV/AIDS Strategy Initiative (SASI) using Centers for Disease Control and Prevention (CDC) surveillance data (Human Rights Watch, 2010; Reif et al., 2014; Reif et al., 2011). Participants were recruited in two ways. One, potentially eligible women who took part in another study that was conducted by the third author were mailed a letter of invitation describing the study and a contact number. Two, recruitment flyers with a study description and contact information were placed at designated sites for self-
referral and the staff/providers at those sites were also encouraged to introduce the study to potential participants and provide them with a flyer. The designated sites included five infectious disease clinics providing health care and social services for people living with HIV. Women were eligible to participate if they: 1) were age 18 or older, 2) self-reported HIV infection, 3) self-designated their race as Black/African American, 4) were able to communicate in English, 5) had one or more dependent child(ren) between the ages of 0-18 years residing in the home, and 6) reported eligibility for public assistance or Medicaid or lived below the federally designated poverty line. Poverty level was measured by the US Census Bureau standards and accounts for family size and the age of the family members ("How the Census Bureau Measures Poverty," 2010).

The Institutional Review Board for human subjects research approved the study. Participants provided signed informed consent after reviewing the details of the study and potential benefits and risks of participating in the study.

### 3.2.2 Data Collection

Data collection occurred at three time points and digital audio recordings were made of all interviews. The content of each collection point and the interviews is summarized in Table 1.
Table 1: Data Collection Time Points

<table>
<thead>
<tr>
<th>Time point</th>
<th>Approximate time</th>
<th>Summary of data collection procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial visit</td>
<td>2 hours</td>
<td>Informed consent process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rapport building interview</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Socio-demographic Assessment Sheet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Outline of goals and use of photography</td>
</tr>
<tr>
<td>2nd visit</td>
<td>1 hour</td>
<td>Photograph content and feasibility Interview</td>
</tr>
<tr>
<td>3rd visit</td>
<td>1 hour</td>
<td>Final in-depth interview</td>
</tr>
</tbody>
</table>

Each interview served a different purpose: (1) building rapport with participants and introducing the goals and use of photo elicitation, (2) examining the content of the photographs and feasibility of the methodology, and (3) exploring the various social and economic complexities of the mother’s lives. Only data related to the photographs and photo elicitation method are presented in this article.

3.2.2.1 Outlining the Goals and Use of Photography

At the initial visit, a rapport building interview was conducted exploring the participant’s experiences of being a mother living with HIV; at this interview each participant was given a 27-exposure disposable camera. The overall goals of the photo elicitation method (“taking pictures”) were explained to participants as follows: 1) to picture or capture the social and economic experiences of your daily life which negatively impact your health or ability to care for your HIV, and 2) to picture or capture the social and economic experiences of your daily life which positively impact your health or ability to care for your HIV. The visit included a discussion about the
social determinants of health in lay terms, including examples, and a brainstorming activity to assist participants in identifying some potential images of strengths and vulnerabilities related to their health that they may wish to capture (Wang, 1999; Wang & Pies, 2004). The participants were then informed of ethical issues in camera use, such as who they could and could not photograph (Wang, 1999; Wang & Pies, 2004). Per the initial research protocol, participants were instructed not to take pictures of persons other than themselves or their own children and were advised to ask their children for permission to photograph them for the study prior to taking pictures (verbal assent). Participants who had disclosed their HIV status to their children and others could indicate on the study consent form whether or not to allow the photographs to be used in research presentations and publications. The consent clearly stated the photographs would be used for the singular purpose of research, so that the purpose or boundary of the project was not blurred to include other uses of visual methods such as advocacy or community engagement (Gubrium, Hill, & Flicker, 2014). In order to minimize the risk of unintentional disclosure, the photographs of participants who had not disclosed their HIV status to their children were not eligible to be used in research presentations and publications.

The technical use of the camera was both discussed and demonstrated and then participants received an addressed and stamped envelope to return the camera to the
first author via the US Mail. The participant was given several weeks to take photographs and a mutually agreed upon return date was established and written down for participant.

Several additional steps were also taken to minimize the risk of any unintentional disclosure of the participant’s HIV status (Cox et al., 2014). The participants were informed that the photographs would be developed under the first author’s name, not their own. They were notified that after the photographs were developed, the first author would review the photographs to ensure they did not contain recognizable persons other than the participant herself or her children. Any photos that violated this standard would be shredded. The first author also emphasized to each participant that she should only take pictures or use the camera in situations in which she is comfortable that her confidentiality could be maintained.

3.2.2.2. Photo Content and Feasibility Interview

Prior to the second data collection point, the first author assigned each of the photographs an identification number. During the second data collection time point, the participant and first author reviewed each photograph and its’ assigned number was verbalized by the first author so that it could be matched with the participant’s description and interpretation in the audio recording. In order to maximize the opportunities for participant contribution to the research process and interpretation of
the visual images, a semi-structured in-depth interview guide was developed in which the participant was asked to talk about each photograph and how she felt it represented the social or economic issues affecting her health (Cox et al., 2014). The structure of the interview was based on a modified SHOWeD framework derived from the Photovoice methodology (Wang, 1999). In the modified SHOWeD framework designed for this study, we asked: What do you See here? What is really Happening here? How does this relate to your health? Is this situation a concern or strength and Why does it exist? What can we Do about it (Wang, 1999)?

In the initial research protocol, the participant was also asked questions about the feasibility and utility of using photography as a data collection and elicitation technique. The questions focused on the women’s understanding of the procedural aspects of using the camera/taking photographs, whether they understood the rationale for taking the pictures and the utility of the pictures in describing the social and economic conditions of their lives. Finally, ownership of the participant-generated photographs was clearly defined and we chose to develop a protocol that emphasized shared ownership in which the participants were each given a hardbound book of their photographs at the conclusion of the study (Cox et al., 2014).
3.2.2.3 Participants and Photographs

Nineteen (N=19) participants were enrolled in the study, however, the tailoring of the visual methods protocol was based on the initial findings from the first five participants that enrolled. The ages for this subset of women ranged from 39 to 57 years (M = 44.4) and each participant reported having 1 or 2 dependent children living in her home (M=1.4). These participants reported living with HIV from 5 to 23 years (M = 16.4) and having a yearly income ranging from 0 to $24,000 (M = $13,552). Their educational attainment ranged from 11 to 16 years (M= 13). The number of photographs taken by each participant ranged from five to twenty-one, for a total of 61 usable photographs.

3.2.3 Data Analysis

Digital recordings of the interviews were transcribed verbatim, proofed for accuracy and kept electronically on a secure computer server. Copies of the digital images from the CD-ROM provided by the photo processor were transferred to the same secure computer server. We began the analysis by importing all the text and visual data into Atlast.ti (Atlas.ti, 2015), a qualitative software program used to assist with data organization and management. We read each transcribed interview and viewed the associated images in their entirety in order to get a sense of the essential features (Sandelowski, 1995) and then used qualitative content analysis to guide the description.
of the feasibility, utility and ethical challenges of photo elicitation as data elicitation technique (Sandelowski, 2000).

3.3 Results

3.3.1 Feasibility

The feasibility of using disposable cameras was well established in the early phase of the study, alleviating some concern by the study team regarding the decidedly dated technology. The participants reported relative ease in using the disposable cameras and none reported technical difficulties or a need for further information on how to use the camera. The women also produced quality photographs in which the subject of the photograph was discernable and focused at relatively minimal cost. The total cost of the disposable camera, film developing, digital CD-ROM of the images and hardback bound book of the participant’s photographs averaged less than $50 USD per participant. Using the disposable camera also allowed for a relatively easy and inexpensive means of producing quality photographs from film, while allowing for the production of a CD-ROM of the images in digital form for storage and dissemination. As such we were able to avoid some of the most pressing ethical implications associated with digital camera-based technologies that produce large numbers of images easily distributed instantly via the internet that may include automated facial recognition and GIS/GPS capabilities (Cox et al., 2014).
The participants assessed three areas of concern regarding the feasibility of the methodology. First, one participant felt that 27 exposures were too many photographs for the assigned exercise. She stated, “Yeah, I [did] thought it was too many. And then I was like ‘dang’ you know, regardless of not paying for this camera…I would have had to hate to let it go to waste...I wanted to take some that meant some to me, that really would make a difference.” Second, despite the brainstorming activity in the initial visit, three of the five women stated they had difficulty discerning what pictures to take, as demonstrated by this women’s statement: “Sometimes I had difficulty on what to take. I was like ‘what should I take a picture of…I don’t know?’” Third, one of the participants suggested that remembering to use the camera took some effort, but denied that additional reminders from the study staff would have helped.

The pitfalls identified by the participants with regard to the feasibility of the photo elicitation method – knowing what pictures to take, the number of pictures and remembering to use the camera - provided an opportunity for the study team to reflect on the study protocol and make adjustments. During the initial visit, additional time was devoted to brainstorming with the participant about potential photographs and some of the photographs taken by the study participants who consented to share their photographs were provided as examples to subsequent participants. The rationale for this shift in strategy was that if the participants had a better sense of what photographs
they could possibly take, the number of photographs would be less intrusive. Any concerns regarding suggestibility from showing examples of previous participant’s photographs were allayed because suggestibility is primarily an issue with regards to retrieved memory (Otgaar, Sauderland, & Petrila, 2013); whereas, we were asking the women to document their current circumstances. Providing such examples can be likened to demonstrating the use of a food diary and providing an example of how to fill it out. Additionally, the participants were encouraged to take a minimum of 8-10 photographs, but assured that they could stop taking the photographs whenever they deemed their ideas were fully represented. Finally, an additional follow-up phone call was included between time point 1 and 2, as a reminder to take the photographs when possible and also to assess whether participants are experiencing any technical difficulties with the camera.

3.3.2 Utility

From both the perspective of the participants and the research team, the utility of photo elicitation was also confirmed early in the study. Without exception, participants identified photo elicitation as a useful and purposive method. One participant stated:

…talking about them [the pictures] was good for me today…it really was, it just…being able to have the pictures afterwards, you know? And to look at them and to see like why I took the pictures, that’s going to be a reminder um, that I was in the study. And you know, I’m just thankful to be in the study.
Additionally the participants demonstrated understanding of the rationale for using photo elicitation as a research method. When asked, the women were able to articulate the rationale for the taking the photographs, as demonstrated by this participant’s response: “You wanted to know about the positive and the weakness, if there was...just to see how it affected what I was doing daily, what had an effect on me.”

Harper (2002) suggests that determining whether the sociological phenomena being explored can actually be photographed is an important first step to assessing the utility of the visual method from the researcher’s perspective. The participant’s photographs of both the positive (strengths) and negative (vulnerabilities) determinants of their health and subsequent verbal interpretation of the images clearly demonstrated to the study team the utility of the method. The participants captured visual representations of the social complexities of their lives and in conjunction with verbal explanations offered detailed descriptions of the impact of those complexities on health at both the individual and community level. **Figures 3 and 4** represent strengths and vulnerabilities (concerns) identified and captured by the women, respectively.
Figure 3: Positive Health Determinant (Strength)

When describing this photograph, the participant stated:

Okay, I took this picture because it is a picture of my big hand. [laughs] But on my hand is my wedding rings and I guess that symbolizes I guess my husband again as well, our marriage is a positive in my life. …so he’s a um, big strength in my life, he is.
Figure 4: Negative Health Determinant (Vulnerability or Concern)

This participant had visually captured her perception of HIV-related stigma and described this photograph by stating:

It’s the steps I can’t, you know, going outward and that means that I’m going to have to go out into the world….It’s always a concern, I’m always concerned about even now…crossing paths with people that have some negative things to say or whisper or may know me or you know, for whatever reason.

Figure 5 is an example of how the women articulated the photograph subjects as determinants of health.
In reference to transportation as a social determinant of health, this participant described her photograph by saying:

That’s my van. My van is a strength for me. A lot of people not fortunate to um...come and go as they please. And for me, it helps me with my doctor’s appointments, that’s a positive, because I know to be on time. Because I know if you don’t be on time, they’ll cancel certain things. And I used to have to ride the bus and sometimes buses are not reliable, not uh, on time you know?

Not only was the information gleaned from the photo elicitation interview a broader, more robust representation of the participant’s social determinants of health than that produced from interviews only, but it also introduced different information and
potential analytical lines for exploration (Guillemin & Drew, 2010; Harper, 2002; Padgett et al., 2013).

3.3.3 Ethical Challenges, Tailoring and Best Practices

To our knowledge, there were no breaches in privacy, no breaches in confidentiality, and no unplanned disclosures of the participant’s HIV status to another person during the study. However, confidentiality and privacy issues specific to mothers, children, and people in their support network did create ethical challenges in using photo elicitation as a data collection methodology. Three out of the first five participants enrolled in the study did not consent to having the photos of them or their children used in presentations or publications. Three out of first five participants also took photographs of identifiable persons other than themselves or their children and these photos had to be shredded per the study protocol.

As such it seemed clear that the women were either not willing (n=1) or able (n=2) to consent to the use of the photographs of themselves or their children in research presentations or publications because they had not disclosed their HIV status to their children and others. This suggested to the research team that the sensitivity of such images in the context of a study about HIV infection was potentially threatening to mothers (Padgett et al., 2013). Paradoxically, several of the mothers took photographs of identifiable adult support people in their lives that had to be shredded per the study protocol.
protocol. As a result, the study team determined that in the interest of minimizing risk, it was most prudent to change the study protocol and consent such that no pictures of identifiable persons, including themselves and their children, should be taken. Rather, if the participants wished to identify certain people in their lives as health determinants, they were encouraged to take photographs of objects such as toys or clothing representing those people.

The consent form was also revised so that participants could “opt in” or “opt out” of having all of their photographs used in research presentation or publications. The rationale for the consent revision was twofold. One, the option to share or not share their photographs in the research forum ensured that participants would have authority over all the shared intellectual property (Cox et al., 2014). The original consent form only asked participants to “opt in” or “opt out” of sharing the images of themselves or their children, while all the other photographs were represented as research data for use at the researcher’s discretion. Two, ensuring the participants the ability to “opt out” of sharing their photographs in the research forum while still providing them with an opportunity to participate in the study created an important and empowering avenue for some mothers to share their personal stories and images in the research interview while minimizing any concerns regarding confidentiality and potential harm associated with unplanned HIV disclosure (Cox et al., 2014; Guillemin & Drew, 2010).
3.4 Conclusions

Visual methods, such as photo elicitation, offer an innovative way to involve vulnerable populations in research and explore the social influences on their health while providing the participants some control in the research process and acknowledging their authority on the subject (Cox et al., 2014; Guillemin & Drew, 2010).

To be sure, however, a method such as photo elicitation poses methodological and ethical challenges requiring researchers to employ a high degree of reflexivity and ethical practices informed by detailed knowledge of the research context and population (Gubrium et al., 2014).

We found two things particularly helpful in aiding our attempts to practice reflexivity and address the challenges detailed in this manuscript. The first was acquiring critical information needed to strategically handle the ethical and methodological challenges unique to visual methods. Such information is available through an on-going dialogue with members of the research ethics committee and the course work, guidelines and scholarly literature available in the disciplines of anthropology, sociology, documentary studies and more recently, public health (Cox et al., 2014; Gubrium et al., 2014; Harper, 2002; Wang, 1999). Additionally, trialing the visual methods protocol with the initial participants was particularly valuable as it provided an opportunity to receive, learn from, and incorporate participant feedback;
anticipate potential pitfalls; and adapt the research protocol for the specific population and setting (Cox et al., 2014). Our experience of using photo elicitation with a highly stigmatized and vulnerable social group of women, while specific to African American mothers living with HIV in the Deep South region of the United States, illuminates some of the many methodological and ethical challenges of visual methods and can be useful a learning tool for future work aimed at incorporating visual methods into health equity research.
4. The Social Determinants of Health for African American Mothers Living with HIV

4.1 Introduction

The vulnerability of African American mothers living with HIV functions at the intersection of gender- (Higgins et al., 2010), race- (Lane et al., 2004), and class-inequality (CDCP, 2010b; Meditz et al., 2011; Ward, 1993); HIV-related stigma (C. Kelly et al., 2009; Sandelowski & Barroso, 2003; Sanders, 2008; Wilson, 2007); and motherhood (Jones et al., 2003; Sandelowski & Barroso, 2003); and multidimensional and transdisciplinary approaches are required to understand these social determinants of their health (Beltran et al., 2011; CDCP, 2010a; CSDH, 2008; Lane et al., 2004). African American women suffer significantly higher HIV infection rates (CDCP, 2015) and tend to die earlier from their infection than their White counterparts (Losina et al., 2009). Poverty is a significant precipitating factor for HIV infection (CDCP, 2010b) and African American women live in poverty more than other subpopulations in the US (U.S. Census Bureau, 2012). Socioeconomic status is a major determinant of the higher morbidity of nonwhite women in the Southern region of the United States (Meditz et al., 2011). Studies also show that HIV-related stigma is linked to poorer mental and physical health outcomes (Logie & Gadalla, 2009).
Motherhood affects the health outcomes of African American women living with HIV. Research exploring the experiences of women living with HIV reveals that motherhood creates added challenges and higher levels of stress for women who must manage their own health care needs while simultaneously acting as caregivers to their children (Jones et al., 2003). Mothers living with HIV also experience difficulty as they attempt to carry out the daily activities of motherhood while managing the symptoms of HIV such as fatigue (Murphy, Johnston Roberts, et al., 2011). Finally, the stigma associated with HIV/AIDS infringes upon their experience of motherhood (Sandelowski & Barroso, 2003). Mothers living with HIV desire to protect their children from HIV-related stigma and experience stress in regard to disclosure of their HIV status to their children, significant others and other family members, fearing that disclosure will make their children vulnerable to stigma (Sandelowski & Barroso, 2003). These mothers also have concerns about the care of their children in case they become ill and die (Sandelowski & Barroso, 2003) and paradoxically they cite motherhood and the desire to protect their children as a source of strength and a reason to live despite their infection (Wilson, 2007). Motherhood, therefore, will be explored in this study as both a potential vulnerability and strength.

A clear appreciation of the link between these mothers’ specific social location and their health outcomes can inform future prevention and treatment efforts. Recent
evidence indicates that early antiretroviral therapy is not only an important treatment strategy for HIV-infected persons and their partners but also an important public health strategy for reducing the transmission of HIV (M. S. Cohen et al., 2011). Interventions to effectively treat mothers living with HIV and keep them healthy will also have far-reaching implications for the health of their children. For example, a recent 12-year study of healthy children and HIV-infected mother dyads found that poorer maternal physical health status was strongly associated with negative outcomes for children, including depression, anxiety, aggression and poor self-concept (Murphy et al., 2012).

Current interventions for mothers living with HIV are few in number, have limitations and fail to address social determinants of health. Prior to the release of the 2011 Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive (UNAIDS, 2011), the interventions specifically aimed at improving health outcomes for mothers living with HIV and reaching beyond just the prevention of maternal to child transmission were few. Indeed, such interventions do not appear in the literature until 2000 (Jirapaet, 2000), almost twenty years after HIV/AIDS was first described in the literature. Further, studies of interventions have been limited by subject attrition as high as 56% (Futterman et al., 2010). Common reasons for attrition include examples of social determinants such as residential instability (Futterman et al., 2010) and HIV-related stigma (Black & Miles, 2002; M. S.
Miles et al., 2003). Finally, none of the interventions for HIV-infected mothers to date have been based on a clear understanding of the gender-, race-, and class-inequality suggested by an intersectional approach, an approach that offers a means for examining how hierarchies of race, gender and class mutually create meaning and interact to produce health inequities (Hankivsky, 2012; U. A. Kelly, 2009; McCall, 2009; Weber, 2006). Most intervention efforts have focused on individual risk behaviors, which are important, but can only partially explain disparities in health outcomes (Lane et al., 2004). Therefore, there is a dire need to address the various social determinants of health of African American mothers living with HIV in order to overcome these obstacles in research. Understanding the intersection of gender-, race- and class- inequality; HIV-related stigma; and motherhood is essential to address the health outcomes of African American mothers living with HIV.

The purpose of this study was to explore the social determinants of health for this population by having African American mothers living with HIV describe the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood in their lives, and its impact on their health experiences. To explore the complexity of these social constructs and their relationships, I used an intersectional approach and qualitative methods of in-depth interviewing, storyline graphs and photo elicitation to provide a comprehensive examination of the meaning that the constructs
hold for participants (Harper, 2002; Mullings & Schulz, 2006; Sandelowski, 1999). These methods engaged participants in describing their own strengths and vulnerabilities in everyday life and illuminated the implications of social and economic contexts for health.

4.2 Specific Aims

4.2.1. Specific Aim 1

Describe the specific social location of African American mothers living with HIV and their mutually constituted social identity at the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood.

4.2.2 Specific Aim 2

Explore the ways in which the unique social identity of African American mothers living with HIV influences their health-related experiences.

4.3 Conceptual Framework

The intersectional approach that will guide the study is based on a model designed for this study and informed by Shi and Steven’s (2010) framework for the study of vulnerable populations titled Motherhood and HIV: An Intersectional Approach (Figure 6). Central to this model is the concept of vulnerability, defined as a “susceptibility to poor health” (p.2). The model represents the intersection of specific factors as mutually
constituted (Hankivsky, 2012; Hill Collins, 1998; Mullings & Schulz, 2006) vulnerability
in which these factors jointly determine health status and access to quality health care.

![Figure 6: Motherhood and HIV: An Intersectional Approach](image)

To illustrate, the conceptual relationships in the intersectional model (Figure 6), a
woman living with HIV is standing at a large traffic intersection with her children in
tow. Her challenge is to cross the intersection safely, protecting both herself and her
children. In the model, 1) the social determinants of health (represented by roads)
intersect to create a mutually constituted vulnerability; 2) the larger the intersection (i.e.,
the more vulnerabilities), the more difficult the woman’s task of managing her condition.
and accessing quality health care, leading to a greater likelihood of poor health outcomes; 3) gender, race and class are socially constructed categories involving sometimes unequal relationships between groups of people, rather than biological or genetic attributes of individuals (Mullings & Schulz, 2006); 4) motherhood (represented by a bridge) may positively influence the ability of a woman living with HIV to navigate the intersection and her subsequent health outcomes; and 5) the health outcomes of the children are at least partially dependent on the health outcomes of the mother and her ability to navigate the intersection.

Previous research has demonstrated the unique and complex health needs of mothers living with HIV (Jones et al., 2003; Murphy, Johnston Roberts, et al., 2011; Sandelowski & Barroso, 2003). This study is the first to explore the mutually constituted vulnerabilities of African American mothers living with HIV and has enhanced our understanding of the intersection of gender-, race-, and class- inequality; HIV-related stigma; and motherhood. Intersectionality, derived from the work of African American feminist social scientists (Hankivsky, 2012; Hill Collins, 1998), and related frameworks examining vulnerable populations (Shi & Stevens, 2010), offer a means of simultaneously examining the mutually constituted (Hill Collins, 1998) effects of social determinants of health (Hancock, 2007; U. A. Kelly, 2011; Shi & Stevens, 2010). Intersectionality does not assume that social determinants of health such as gender-,
race- and class- inequalities simply accumulate to create a triple threat (Mullings & Schulz, 2006). Rather, the constructs are mutually constituted, varying as a function of one another depending on the particular gender, race and class to which an individual belongs (Mullings & Schulz, 2006). For example, the intersection of social determinants of health for an African American HIV-infected mother living in poverty may function quite differently than that of an African American HIV-infected father living in poverty. That is, race and class are gendered and may operate differently to produce health outcomes (Mullings & Schulz, 2006). Intersectionality also challenges the idea of gender as the primary dimension of inequity or social determinant of health; rather, it acknowledges multiple dimensions of inequity that can shape health experiences (Hankivsky, 2012).

The theoretical assertions and assumptions of this model are drawn from the literature and prior research demonstrating how each of these social determinants individually impacts health outcomes; however, the framework was designed from my perspective as researcher in which my own social location as a white, upper-middle class female researcher and in particular, the power I am generally afforded to act as a by my whiteness, socioeconomic position and educational status is a work (Allen, 2006). In effort to keep my external vantage point from the dominant social location explicit and also ensure opportunities for the participants to describe their own challenges and
resources used to counter those challenges (Morris, Leung, Ames, & Lickel, 1999; Spiers, 2000), specific theoretical and methodological decisions were made in the study design.

An important theoretical decision in the study design was the selection of intersectionality as a framework for the study. Intersectional scholars recognize heterogeneity in health and illness response, emphasize social context and the power differentials inherent within those contexts, and employ multi-axis analyses needed to expand our understanding of health inequities (Bauer, 2014; Caiola et al., 2014). Equally important were the methodological choices made in the study design. I used innovative techniques such as photo elicitation and storyline graphs to engage the participants in identifying and describing their own strengths, vulnerabilities and health-related experiences (Bugos et al., 2014; Harper, 2002; Sandelowski, 1999). My use of these methods is detailed in the Design section below, but it is important to note that subject participation not only illuminates participant’s self-understandings (Morris et al., 1999), they are useful in facilitating and sustaining change when addressing health inequities or vulnerabilities (Gupta, Ogden, & Warner, 2011). A comprehensive approach like intersectionality, actualized in qualitative descriptive methods such as storyline graphs and photo elicitation, is an innovative way of fully understanding the social determinants of health specific to African American mothers living with HIV and can
provide rich data and insights into interacting social processes and their health-related experiences over time.

4.4 Approach

4.4.1 Design

I used a qualitative descriptive design employing in-depth interviews, storyline graphing and photo elicitation with 18 African American mothers living with HIV. I collected data at three points for each study participant: initial, 6 and 8 weeks.

In-depth interviews were the principal method of data generation. In-depth qualitative interviews are well suited to an intersectional approach because they allow participants the opportunity to give in-depth descriptions of complex phenomena and their meanings and relationships to one another (Mullings & Schulz, 2006). The interviews explored the gender-, race-, and class- inequality; HIV-related stigma; and motherhood experiences of African American mothers living with HIV; and any other social determinants of health identified by participants. Gender-, race-, and class- inequality; HIV-related stigma; and motherhood were not intended as pre-selected variables, but broad categories of social determinants of health about which to elicit information (Sandalowski, 2000). The goal was to describe how individual participants experience and manage in the context of specific social determinants.
Storyline graphs and photo elicitation accompanied the interviews. Storyline graphs are a tool in which the participant is asked to select and reflect on key life events so that they may be placed on a time line (Sandelowski, 1999). For the purposes of this study, participants were specifically asked to select and reflect on health-related key events such their HIV diagnosis and pregnancies. The graphs were used to elicit information from the participants about their health experiences and different aspects of those experiences over time, reveal their temporal relationships to one another as well as demonstrate points at which particular health events intersect or diverge (Sandelowski, 1999).

Photo elicitation is a qualitative interviewing technique in which the researcher uses photographs during the research interview to elicit information from the participants (Bugos et al., 2014; Harper, 2002). Although the source of the photographs can vary (Harper, 2002), I asked participants to conceive of, take and describe photos they believed best represented the social and economic complexities affecting their health. My use of photo elicitation was partly inspired by a community-based participatory action research methodology called Photovoice which is grounded in feminist and critical theory (Wang, 1999). Like Photovoice, photo elicitation honors the participant’s knowledge and lived experience of health and health conditions, offers an element of participant control in the photographic and analytic processes used to
identify strengths and vulnerabilities and allows participants to be active members in the research process (Guillemin & Drew, 2010; Harper, 2002; Padgett et al., 2013; Wang, 1999). The visual medium of photographs offers an alternate way for participants to capture and express the social and economic complexities of their lives. Participants were instructed to take photographs of their social and economic experiences, both strengths and vulnerabilities, which may appear in pictures illustrating such things as transportation, housing conditions and church communities. The photographs were then used to stimulate dialogue regarding how these factors affect their health-related experiences (Wang, 1999). Together, in-depth interviews, storyline graphs and photo elicitation provided participants a variety of opportunities to detail the complex intersection of social determinants of health over time.

4.4.2 Setting

Participants were recruited from the Triangle area of North Carolina (NC), in the cities of Raleigh/Durham/Chapel Hill and the surrounding area. In a recent report from the Southern HIV/AIDS Strategy Initiative (SASI), NC was designated as one of the “target states” in the US because, according to Centers for Disease Control and Prevention (CDC) surveillance data, it has been disproportionately affected by the HIV epidemic in recent years as a result of overall poor health status, high poverty rates, and a cultural conservatism fostering HIV-related stigma (Reif et al., 2014; Reif et al., 2011).
Additionally, Black/African Americans disproportionately represent HIV cases in North Carolina (67.8%) as compared with other race/ethnic groups (CDCP, 2013).

4.4.3 Sample and Sampling Plan

A purposeful sampling technique was used to recruit participants for this study. Women were eligible to participate in the study if they: 1) were aged 18 or older, 2) self-reported HIV infection, 3) self-designated their race as Black/African American, 4) were able to communicate in English, 5) had one or more dependent child(ren) between the ages of 0-18 years residing in the home, and 6) reported eligibility for public assistance, Medicaid or living below the federally designated poverty line. Poverty level was measured by the US Census Bureau standards and accounts for family size and the age of the family members ("How the Census Bureau Measures Poverty," 2010).

4.4.4. Recruitment and Retention

For study recruitment, I worked closely with an experienced HIV researcher who has long-standing relationships (10 plus years) with the local agencies serving persons living with HIV in North Carolina and who has been successful in recruiting for numerous studies conducted in this geographical area, including the recruitment of 100 HIV-infected women into a stigma intervention study. Initially, we sent a letter describing the study (Appendix A) via the United States Postal Service (USPS) to potentially eligible participants with whom she had worked with in previous studies to
inquire about their interest in participating. The letter included contact information and encouraged potential participants to contact us directly regarding the study.

The second strategy was placing recruitment flyers at designated sites for self-referral. The designated sites included five infectious disease clinics providing health care and social services for people living with HIV in the central region of North Carolina. In addition, the staff/providers at these sites were encouraged to introduce the study to potential participants and provide them with a flyer. The flyer detailed the basic eligibility requirements and instructed the women to call or email me. From each of these entry points into the study, mail recruitment and self-referral flyers, I followed the participant flow diagram displayed in Figure 7.
If a participant was interested in the study and she was fully eligible based on the Screening Tool (Appendix B), contact information was gathered and a meeting scheduled at the location of her choice.

**4.5 Data Collection Instruments and Procedures**

**4.5.1 Demographic Data**

At the initial data collection session, I used the Sociodemographic Assessment Sheet (Appendix C) to collect data on gender, age, race and ethnicity, education,
occupation/employment, income, marital status, number of children, ages of children under 18 years of age residing in the home, HIV history, and basic health indicators.

4.5.2 Interviews

Participants gave three in-depth interviews. Three interviews were used so that I could complete the consent process, build rapport with participants over time, outline the goals and use of photography, create individual storyline graphs, examine the content of the photographs with the participants, and explore the various social and economic complexities of the mother’s lives. There are no established guidelines for number of interviews or spacing between interviews with methods like photo elicitation. A space of six (6) weeks between the initial rapport building interview and the photograph content interview was chosen allowing for a reasonable amount of time for mothers to thoughtfully photograph images important to them, mail the camera back and have the photographs developed, without extending contact time excessively and risking attrition or loss of interest. The final interview was scheduled within 2 weeks from the second interview so that the participant could still retrieve from memory the information discussed in the photograph content interview, and draw on it to inform her responses to questions about the social and economic complexities of her life and their effects on her health.
Interviews lasted no more than 2 hours and were conducted in one of the following places depending on the participant’s preference: her home or a private room on the university campus. After each interview, the participant and I mutually agreed upon the date and location of the next session. Bus or parking passes were provided to the participant if travel was required to attend the interview. Finally, I followed up with a reminder phone call one to two days prior to the next scheduled interview. Participants received gift cards totalling $50 US dollars or less depending on the number of interview sessions completed. If participants completed all three interviews they also received a hardback photobook of their photographs at the end of the third session. Sampling ended when no new themes seemed to appear in the analysis following multiple interviews (Marshall & Rossman, 2011).

4.5.2.1 Rapport Building Interview

Interviews began using a broad question, “Please tell me about your experiences of being a mother living with HIV,” that would encourage the participant to use a narrative story-telling style and allowed for the initiation of rapport building during the initial visit. Additionally, global questions were asked about what ways, if any, HIV affects the woman’s ability to mother, and how mothering has affected her ability to manage her health condition (Appendix D). In order to more fully understand the temporal relationship between specific health-related experiences such as her HIV
diagnosis, pregnancy(ies), and other key health-related experiences they were plotted on a storyline graph (Appendix H). The graphs provided information about each mother’s individual trajectory and allowed for the comparison of trajectories across mothers (Sandelowski, 1995). The participant was asked to reflect on the key events in her life as a mother, provide the approximate age in which that experience occurred and assign an “emotional value” (i.e., positive feelings, neutral feelings, negative feelings) to each specific experience she chose to identify. She was then asked to reflect on the key events in her life living with HIV, provide the approximate age at which that experience occurred and again assign it an emotional value. The age of each of these key experiences was plotted on the x-axis and the emotional value was plotted on the y-axis of the storyline graph in order to develop a motherhood and HIV trajectory for each participant. The goals of photo elicitation technique were to discuss her self-identified social determinants of health and capture those determinants she deemed as strengths and vulnerabilities related to her health as an African American mother living with HIV (Wang, 1999; Wang & Pies, 2004). In the first session, each participant was given a disposable camera with at least 27 exposures for the photo elicitation component of the study, and the participant and I brainstormed ideas for taking pictures, discussed ethical and technical issues related to using the camera, and conferred on the time frame for mailing the camera back to me (Wang, 1999; Wang & Pies, 2004) (Appendix E).
4.5.2.2 Photo Content Interview

At the second data collection time point, the participant and I reviewed copies of her photographs. Each participant was asked to describe the photographs and why/how she felt they represented the social or economic issues affecting her health. In order to provide structure to the discussion, the participants were instructed on using a modified SHOWeD framework (Appendix F): What do you See here? What is really Happening here? How does this relate to your health? Why does this situation, concern, or strength exist? What can we Do about it (Wang, 1999)? The content from the SHOWed data was then used to identify themes, vulnerabilities and strengths in the participant’s health-related experiences (Rhodes et al., 2008; Wang, 1999; Wang & Pies, 2004).

4.5.2.3 Final In-depth Interview

At the last data collection point, the participant was asked open-ended questions to explore the intersection of gender-, race-, and class- inequality; HIV-related stigma; motherhood; and any other social determinants of health they identified (Appendix G). Again, global questions were used in order to encourage the participant to use a narrative story telling style. For example, as a means of exploring HIV-related stigma, race/racism and motherhood, I asked, “How do you feel others treat you as an African American mother living with HIV?” Such a question allowed for her to describe any or all aspects of these determinants to whatever degree she felt compelled. In order to fully
understand the health implications of each of the determinants, I would probe further about any specific experiences of inequality (e.g., racism) described by the participant and ask if she felt such an experience impacted her health, and, if so, how it impacted her health.

4.5.3 Ethical Conduct

The Institutional Review Board for human subjects research at Duke University Medical Center reviewed and approved all phases of this study.

4.5.4 Data Preparation

Professional transcriptionists transcribed the digitally recorded interviews verbatim and I then verified each of them for accuracy. I kept the interview recordings, transcribed interviews, field notes, digital photographs and demographic data electronically on a secure server at Duke University School of Nursing. Each piece of data was labeled by source (participant number) and type (interview, photograph).

4.6 Data Analysis

4.6.1 Demographic Data

Descriptive statistics were performed on the participant demographic characteristics.
4.6.2 Qualitative Data

In an attempt to expand both the conceptual and analytic approaches to an intersectional framework and also fully describe the intersection presented in the conceptual model, I used a phased approach and several qualitative analytic techniques to examine the relationship of the participant’s social determinants of health with one another, those intersecting determinants in relation to the participants’ overall self-assessment of health and the trajectories of motherhood and HIV over time. In phase one, I used content analysis to construct and describe the trajectories of motherhood and HIV over time (i.e., storyline graphs), identify the themes in the photo elicitation data and describe the intersection of gender-, race-, and class- inequality; HIV-related stigma; and motherhood for African American mothers living with HIV. In phase two, I took a case-oriented approach and used the findings from the content analysis to construct a vector model reflecting each individual participant’s perceptions of their social determinants of health and overall self-assessment of health. In phase three, I used qualitative comparative analysis to make cross-case comparisons of the participant vector models.

4.6.2.1 Phase One of Qualitative Analysis

I began the analysis by importing all the photographic and text data into Atlas.ti (Atlas.ti, 2015), qualitative data analysis software that assists researchers to organize and
analyze non-numerical data, including digital photographs. I read each transcribed interview in its entirety in order to get a sense of its essential features, noting specific references to photographs, and wrote a brief abstract of the distinctive elements (Sandelowski, 1995). At this time, I also constructed the individual participant storyline graphs based on the participant’s descriptions of the key events in their life as a mother living with HIV.

I then used a combination of coding methodologies (structural, descriptive, and magnitude coding) to help assess the participant’s perceptions of their social determinants of health and social location (M. B. Miles, Huberman, & Saldana, 2014; Saldana, 2013). Being an African American mother living in poverty with HIV generally makes a woman more vulnerable to poor health outcomes (Shi & Stevens, 2010); however, there is likely a great deal of variation in the assessed vulnerability and health-related experiences. The participant’s framing of her social determinants of health as strengths or vulnerabilities, and the meaning those determinants hold as she compares herself to others and considers her own social context can shed light on her subjective experience of health inequality or vulnerability (Bottero, 2004; Irwin, 2015; Kahneman & Tversky, 2000). In other words, a participant’s own assessment of her overall health vulnerability and subjective social location may not only help anticipate her health experiences, but also act to shape them (Bottero, 2004; Irwin, 2015; Kahneman &
Tversky, 2000), and these coding methodologies helped to describe the participant’s perceptions of her social determinants.

The primary concepts outlined by the intersectional framework - race-, gender-, class- inequality, HIV-related stigma and motherhood - were operationalized as health determinants and assessed in the first cycle of coding using structural and magnitude coding (Saldana, 2013). Table 2 contains the operational definitions of the *a priori* structural codes used for coding the social determinants of health as well as the outcome or response constructs drawn from the conceptual model.

**Table 2: Social Determinants of Health Coding Scheme**

<table>
<thead>
<tr>
<th>Determinant</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>~Class</td>
<td>Participant indicated that she has the material resources needed to both promote and protect her health and the health of her children</td>
</tr>
<tr>
<td>~Gender</td>
<td>Participant indicated that she is treated equally in comparison to men and her gender positively impacts her health experiences and/or her health outcomes</td>
</tr>
<tr>
<td>~HIV-related Stigma</td>
<td>Participant indicated that when people know or believe she has HIV/AIDS she is treated equally to others and this treatment positively impacts her health experiences and/or health outcomes</td>
</tr>
<tr>
<td>~Motherhood</td>
<td>Participant indicated that the relationship she has with her dependent children is positive in nature and positively impacts her overall health</td>
</tr>
<tr>
<td>~Race</td>
<td>Participant indicated that in comparison to people of other races she is treated equally as a Black/African American and her race positively impacts her health experiences and/or her health outcomes</td>
</tr>
<tr>
<td>Class</td>
<td>Participant indicated that she does not have the material resources needed to both promote and protect her health and/or the health of her children</td>
</tr>
<tr>
<td>Determinant</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gender</td>
<td>Participant indicated that she is treated unequally in comparison to men and her gender negatively impacts her health experiences and/or her health outcomes</td>
</tr>
<tr>
<td>HIV-related Stigma</td>
<td>Participant indicated that she perceives or experiences prejudice, discounting, discrediting or discrimination because people know or believe she has HIV/AIDS</td>
</tr>
<tr>
<td>Motherhood</td>
<td>Participant indicated that the relationship she has with her dependent children is negative in nature and negatively impacts her overall health</td>
</tr>
<tr>
<td>Race</td>
<td>Participant indicated that in comparison to people of other races she is treated unequally as a Black/African American and her race negatively impacts her health experiences and/or health outcomes</td>
</tr>
<tr>
<td>Non-determinant</td>
<td>Participant indicated that the determinant in question does not play a role or is not a factor in her health experiences and outcomes; it is neither a strength nor vulnerability; neither a positive nor a negative</td>
</tr>
<tr>
<td>Mixed determinant</td>
<td>Participant indicated that the determinant in question both negatively and positively influences her health experiences and outcomes; it is not dichotomous</td>
</tr>
</tbody>
</table>

### Determinant Configurations

<table>
<thead>
<tr>
<th>Determinant Configurations</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mutually Constituted Strengths</td>
<td>Participant indicates that the intersection of two or more social determinants concurrently elicit a positive health response or impact her health in a positive way</td>
</tr>
<tr>
<td>Mutually Constituted Vulnerabilities</td>
<td>Participant indicates that the intersection of two or more social determinants concurrently elicit a negative health response or impact her health in a negative way</td>
</tr>
<tr>
<td>Opposing Determinants</td>
<td>Participant indicates that a social determinant, positive or negative, influences another determinant in an opposing fashion</td>
</tr>
</tbody>
</table>

### Health Self-Assessment

<table>
<thead>
<tr>
<th>Health Self-Assessment</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>~ Definition of Health</td>
<td>Participant indicated that she does perceive herself as healthy based on her own definition of health</td>
</tr>
<tr>
<td>Definition of Health</td>
<td>Participant indicated that she does not perceive herself as healthy based on her own definition of health</td>
</tr>
</tbody>
</table>
Structural coding is a deductive form of coding that allowed me to use an a priori set of codes derived from the intersectional framework (Saldana, 2013). In addition to the structural coding, I used magnitude codes (Saldana, 2013) which were dichotomous, and suggested the valence (positive or negative) of the health determinants as either strengths or vulnerabilities, respectively (Britt & Evans, 2007; Saldana, 2013). The direction of the health determinants as strengths or vulnerabilities was coded using the participant’s self-assessment of the impact of the determinants in their daily lives and an analysis of the text describing the determinant. The constructs were represented as uppercase letters for vulnerabilities and uppercase letters preceded by a cedilla (⊥) for strengths (Britt & Evans, 2007). Please see Table 3 for an example of the coding.

**Table 3: Magnitude or Valence Coding Scheme**

<table>
<thead>
<tr>
<th>Social Determinant of Health</th>
<th>Magnitude or Valence</th>
<th>Symbol</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>Vulnerability</td>
<td>R</td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td>⊥R</td>
</tr>
<tr>
<td>Class</td>
<td>Vulnerability</td>
<td>C</td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td>⊥C</td>
</tr>
<tr>
<td>Gender</td>
<td>Vulnerability</td>
<td>G</td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td>⊥G</td>
</tr>
<tr>
<td>HIV-Related Stigma</td>
<td>Vulnerability</td>
<td>S</td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td>⊥S</td>
</tr>
<tr>
<td>Motherhood</td>
<td>Vulnerability</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td>⊥M</td>
</tr>
</tbody>
</table>

Descriptive coding was used for any data in which structural codes did not apply. Descriptive coding is an inductive form of coding in which the code is derived from the data itself and identifies the topic about which the participant is talking or
writing (Saldana, 2013). The rationale for using descriptive coding was that some of the data, particularly that data elicited from the participant’s photographs, may not be explained or easily coded by the conceptual framework and structural coding (Hsieh & Shannon, 2005) and I wanted to capture any novel determinants that the conceptual framework did not predict.

After the initial coding, I examined the participant’s descriptions of intersecting social determinants and their concurrent impact on their health experiences. Intersecting social determinants were determined using the Atlas.ti (Atlas.ti, 2015) analytic co-occurrence tool. One limitation of this tool is that it only reflects bi-dimensional co-occurrence (i.e., when two determinants intersect). In order to determine when multiple determinants intersected, each cell in the co-occurrence output was examined for the redundancy of participant quotations and when quotations occurred in multiple cells they were reclassified as multidimensional intersections. For example, when the same quotation was found in the cells determinants Race and Class as well as Class and HIV-related stigma, the quotation was reclassified as the multidimensional intersection of Race, Class and HIV-related Stigma. Once the intersections of social determinants were establish and the descriptive codes from the first cycle of coding were complete, I reanalyzed the data and developed larger categories of data which were then used to create themes using pattern coding (Saldana, 2013).
Analysis of the story line graphs created from the interview data included both individual and comparative analyses (Sandelowski, 1995). I visually analyzed each participant’s trajectory (with-in case analysis) and looked for the temporal location of key health-related experiences, their relationship to each another, where they appear to intersect and/or diverge from each another and the assigned emotional values of those health-related experiences. I then visually analyzed patterns across trajectories (cross-case analysis) to help me develop health trajectories themes (M. B. Miles et al., 2014). Specifically, I looked for patterns or regularities in the key health-related experiences with regard to time, place, assigned emotional value or relationships (Sandelowski, 1995). Phase one of the analysis was done using the interview and visual data across the entire sample.

4.6.2.2 Phase Two of Qualitative Analysis

Phase two of the analysis used the findings generated in phase one and a case oriented approach in order to gain a greater understanding of the how each of the five social determinants simultaneously intersect to impact the health experiences for the individual participants. Results and experience from the pilot study and phase one of the analysis helped me to understand that constructing interview questions and eliciting participant responses that simultaneously examined all five social determinants from the conceptual model (i.e., gender-, race-, and class- inequality; HIV-related stigma; and
motherhood) as well as the determinants generated from the participant perspective is extremely difficult. In an effort to address this and using the Vector Model of Complexity as a guide (Safford et al., 2007), I constructed a case-oriented analytic approach that examined and contrasted the relationship of each participant’s perceptions of her social determinants of health to her overall self-assessment of health. This allowed me to examine the way a participant frames her social location and interprets her health-related experiences (Britt & Evans, 2007; Irwin, 2015). The Vector Model of Complexity uses vector physics to conceptualize and visualize health determinants as intersecting at a common axis and exerting force with both magnitude and direction (Safford et al., 2007). I adapted the Vector Model of Complexity to conceptualize and visualize the valence and configuration of a participant’s social determinants of health (Figure 8) as strengths and vulnerabilities in the context of her self-assessment of health to arrive at her overall social location with regards to health (Safford et al., 2007).
Figure 8: Example Vector Models for Social Determinants of Health

In the model, the narrow blue arrows represent vector forces of each of the health determinants in the intersectional model: race (R or ~R), class (C or ~C), gender (G or ~G), HIV-related stigma (S or ~S) and motherhood (M or ~M). The plane at which the vectors intersect represents the participant’s health experience, described as the health axis (H). The red vector always exerts force and direction toward greater vulnerability because it represents the health vulnerability of living with HIV. The large block blue arrow represents the participant’s self-assessment of her health as positive or negative and the summary of the health determinant vectors. Greater vulnerability is depicted as a path trajectory below the axis and lesser vulnerability or strengths are depicted as a path above the axis. Determinants exerting positive force in the participant’s health experiences point upward and the determinant identified by the participant as most positive is green in color. Determinants exerting negative force in the participant’s
health experiences point downward and the determinant identified by the participant as most negative is orange in color. I would like to emphasize that the mathematical relationship between the vectors cannot be calculated but the relationships between the different determinants for individual participants are theoretically relevant for visualizing and assessing vector patterns within and across participants. This analysis helped me to hypothesize about the relationships, patterns and paradoxes between their assessed vulnerabilities and strengths (Safford et al., 2007).

4.6.2.3 Phase Three of Qualitative Analysis

During this phase of analysis, I used second cycle pattern coding and cross-case analysis (Saldana, 2013). For the cross-case analysis I used a comparative analysis table (Table 4) to hypothesize about the different typologies or ways that participants frame their subjective social location based on the different combinations of the determinants and their self-assessment of health (Britt & Evans, 2007; Irwin, 2015; M. B. Miles et al., 2014).

Table 4: Hypothetical Comparative Analysis

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Race</th>
<th>Class</th>
<th>Gender</th>
<th>HIV-related stigma</th>
<th>Motherhood</th>
<th>Health Assessment</th>
<th>Social Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>M</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>-R</td>
<td>-C</td>
<td>~G</td>
<td>S</td>
<td>~M</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>R</td>
<td>C</td>
<td>~G</td>
<td>S</td>
<td>~M</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>R</td>
<td>C</td>
<td>~G</td>
<td>S</td>
<td>M</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>M</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

Adapted from Britt & Evans (2007)
4.7 Assuring Trustworthiness of Qualitative Descriptive Study

The trustworthiness of the study was enhanced in several ways. To begin, I honed my skills in qualitative methods and analysis by taking two doctoral level courses dedicated to these subjects, receiving mentorship from three faculty experts in qualitative methods and analysis, and conducting a pilot study to refine my qualitative interviewing skills. Study reliability is the process of ensuring consistency throughout the design independent of a single researcher and throughout the duration of the study (M. B. Miles et al., 2014). The study’s design and its congruence with the specific aims and connectedness to theory helped in strengthening the reliability of the study (M. B. Miles et al., 2014). Additionally, multiple occasions and forums for peer and mentor review helped to shore up the reliability of the study. In an effort to ensure the qualitative design was credible and valid (i.e., credibility), I defined the concepts in the conceptual framework, ensured the interview guide/measure reflected those concepts, and attempted to give context-rich descriptions (M. B. Miles et al., 2014). To enhance the confirmability of the study, I retained the data and created an audit trail detailing the methods (such as the sampling plan and semi-structured interview guide) and analytic procedures (such as data coding and condensing procedures) such that the data could be reanalyzed (M. B. Miles et al., 2014). Moreover, I attempted to heighten the confirmability by my own attempts to practice reflexive thinking, become self-aware
through participant and faculty mentor feedback, and journal about my personal biases (M. B. Miles et al., 2014). I enhanced the dependability of the study by meeting biweekly with my mentor to review findings, assess that the analysis reflected the data collected and explore issues of divergent findings (Marshall & Rossman, 2011). I deliberately sought and considered alternative hypotheses and disconfirming evidence, sought faculty feedback on the analytic process and attempted to present the findings in a coherent and systematic way (M. B. Miles et al., 2014). Finally, I enhanced the transferability of the qualitative strand by providing rich descriptions of the findings so that readers may assess the transferability by connecting the findings, whether they are confirming or disconfirming, to the conceptual framework (M. B. Miles et al., 2014).

4.8 Results

I present the findings according to the phases of the analysis. In the first section of the findings, I present the description of the demographics of the sample and the content analysis of the photo elicitation exercise, the storyline graphs and the interviews. In section two of the findings, I present three exemplar vector models constructed from the data that reflect the participant’s perceptions of their social determinants of health and their overall self-assessment of health. In section three of the findings, I present typologies, or social location frames, identified using the cross-case analyses of the individual vector analyses.
4.8.1 Phase One: Content Analysis

4.8.1.1 Sample

The data for this study were collected between April 2013 and April 2015. Tables 5 and 6 summarize demographics of the sample. Nineteen (19) participants were enrolled in the study but during the third interview for one of the participants, it became apparent that she did not fully meet the eligibility requirements because her child was no longer in her custody. As such, the final sample consisted of eighteen (18) participants. I completed a total of 48 interviews with the 18 participants. The number of usable photographs taken by each participant ranged from zero (0) to twenty-five (25), for a total of one hundred eighty four (184) usable photographs. Photographs were considered usable if they met the criteria detailed in the study protocol and consent regarding identifiable persons, the photograph quality was sufficient to distinguish the photograph content when developed and the photographs were taken by the participant themselves. Five (5) of the participants reported that their children had taken at least some of their photographs. The photographs that were not usable were shredded per the study protocol. Per the participant’s preference, fifteen (15) of the participant interviews occurred in a private room at the Duke School of Nursing (DUSON) and the remaining thirty-three (33) occurred at the participants’ home.
Each participant identified herself as being African American/Black, female, and living with HIV. Each participant also reported being eligible for public assistance/Medicaid and/or living below the poverty line. At the time of enrollment in the study, the age of the participants ranged from 25 to 57 years ($M = 41.5$), the number of years they had been living with HIV ranged from 5 to 32 years ($M = 13$) and their educational attainment ranged from 11 to 16 years ($M = 12.56$). The participants reported having between one (1) and five (5) dependent children living in their home ($M = 1.6$). Four (4) of the participants reported parenting children other than their biological children, such as grandchildren, stepchildren or nieces/nephews and one of the participants was pregnant.

Of the 18 participants, I was able to complete all three interviews with fourteen (14) of the women and storyline graphs with eleven (11) of the women. Two of the participants were lost to follow up after the first time point, one participant was lost to follow up after the second time point and one participant’s third interview had to be suspended midway through because she became emotionally distressed and I needed to implement the study’s crisis intervention protocol.
Table 5: Description of Cases

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<th>Years Living with HIV</th>
<th>Education (years)</th>
<th>No. Interviews &amp; Location</th>
<th>No. Usable Photos</th>
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DUSON = Duke University School of Nursing

Table 6: Participant Demographics (n=18)

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<td>5-32</td>
</tr>
<tr>
<td>Educational attainment (years)</td>
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<td>11-16</td>
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<tr>
<td>No. Dependent Children</td>
<td>1.6</td>
<td>1-5</td>
</tr>
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4.8.2.2 Content Analysis of Photo Elicitation Interviews

In this section of the findings, I present the themes identified specifically from participants’ perspectives of their social determinants of health using the data generated in the photo elicitation interview. The photo elicitation interview was completed with 16 of the 18 participants and the goal of this section is to ensure the voice of the participant’s lived experience of vulnerability and strength as it relates to their health. At a 3:1 ratio, the participants chose to photograph positive health determinants (154) as opposed to negative health determinants (49), identifying a total of two hundred and three (203) health determinants. The total number of determinants identified is greater than the actual number of photographs (184) taken because some of the photographs were coded as more than a single determinant per the participant’s descriptions. Not all of the photographs depicted determinants of health that are categorized as social determinants. For example, participants depicted a number behavioral and/or lifestyle determinants such as eating habits and exercise in their photographs. The social determinants of health identified primarily as positive health determinants by the participants included social support, religion, animal companions, and the physical environment. The social determinants of health identified as mixed determinants, having both positive and negative qualities, were transportation and housing. Each of these social determinants is presented along with definitions and exemplars.
4.8.2.2.1 Social Support

The participants photographed and described people or objects representing the people in their social network that they felt cared for them and/or offered assistance when needed. While several of the photographs of people had to be shredded because they were identifiable images of people, the participant was still asked to describe the photograph using the modified SHOWeD framework. The photographs of the objects representing people were retained and also discussed.

Participants primarily described how their family members and significant others offered them emotional support and encouraged them to care for themselves and their health. One participant took a photograph of her wedding rings and explained that the photograph represented her husband (Figure 9). She further explained that her husband was HIV-negative and described the emotional support he provided when she disclosed her HIV status:

But I had to let him know and that was like a sad moment you know? But he turned it into a happy moment because at the end of the conversation I was laughing, so he’s a um, big strength in my life, he is. And he helps me out a lot… (Participant 003, Interview 2)
Another participant took a photograph of her husband’s work shirt (Figure 10) and stated:

It’s a picture of my husband’s work shirt...and it symbolizes him you know just being a strong individual in my life and giving me the support that I need...yeah because he’s- he encouraged me a lot to keep up my health. (Participant 018, Interview 2)
The support person in one participant’s life was also portrayed as role model for health. She took a photograph of her uncle that lives with her and stated:

I see someone positive, always been a positive role model. Um...I don’t care he does dialysis, three days a week. And I, if I didn’t know him, I would have never tell it, he never complains. If he is sick or hurting I wouldn’t know it you know? He never uh...‘oh I’ve got to go to dialysis’ ‘oh da da da ‘none of that. He just a positive role model. He just a positive-I look at his situation, I look at mine and I’m like pssh. You know, he lifts me up a whole lot. (Participant 002, Interview 2)

Whether the support people in the lives of participants offered encouragement, emotional support or a role model, they were portrayed as positively impacting their health and helping them to cope with their HIV diagnosis.

4.8.2.2 Religiosity

The participants photographed objects representing their spiritual beliefs in a higher power and described the beliefs as positively impacting their health. In this
sample, the participants universally represented their spiritual beliefs in a higher power with objects associated with Judeo-Christian religious practices and commonly described their affiliation with Black Churches (churches serving primarily African Americans), representing non-organizational religiosity and organizational religiosity, respectively (Ludema et al., 2015). Bibles, Christian churches, a daily devotion book, prayers imprinted on a plaque and a pillow, a church piano, a guardian angel figurine, and a church bulletin were among the numerous objects photographed by the participants. They described their spiritual and religious beliefs as positively impacting their health in several ways. They explained that their beliefs offered them guidance, additional social support, and opportunities to serve others.

A number of the participants described the ways in which their religious beliefs provided them guidance in coping with their HIV and life generally. They used words like “balance,” “focus,” “enlightenment,” and “encouragement” to describe the impact of the guidance provided from their religious tradition. For example, one participant described the photograph (Figure 11) of the guardian angel figurine below, explained that she believed her guardian angel was her grandmother and stated that her guardian angel guided her in the following way:

Um, [a guardian angel] gives you guidance and you know understanding, pretty much. You know- even though you got this disease, don’t let it overcome you. Don’t let it get you out there. Don’t let you get depressed just push, push, you got to fight. You got to fight for your life, that’s what that angel represents. God
is um…let me see, basically God just finding someone to take you know look after me. (Participant 016, Interview 2)

Figure 11: Religiosity Photograph 1

Other participants described their religious beliefs as the means for accessing additional social support, which in turn positively impacts their health. One participant photographed a church bulletin and reported that her church offered her a welcoming, nonjudgmental community in which to participate. She stated, “…they don’t judge you. They don’t look at the color of your skin, your race or I mean nothing and your health-sick or bad- they welcome. They welcome you open hands…” (Participant 013, Interview 2). Another participant took a picture of her Bible cover and stated, “I’ve been in the church since I was a baby. (P laughs) You know I’ve been- it’s been my whole life through- church. Church- I think church- my church family and God has kept me alive.” (Participant 016, Interview 2).
Religious affiliation was also described as offering participants the opportunity to serve others. For example, one participant took a picture of her church (Figure 12) and listed the many church activities she participated in such as tutoring children and providing food for others. She explained that these ministries and serving others positively impacted her health in the following way:

... so, my church is my life now. So that’s a good strength....because I don’t focus on my illness. Um I don’t have any… what do they call ‘em, side effects from the medication so I don’t really think about it. (Participant 006, Interview 2)

Figure 12: Religiosity Photograph 2

Guidance, additional social support and opportunities for service to others were all aspects of the participant’s religious and spiritual practices which were distinguished as a positive social determinant of health.
4.8.2.2.3 Animal Companions

In addition to their social networks, many of the participants photographed and described the relationships and support they received from their animal companions. Almost one third of the participants (5 out of 16) chose to photograph their dog, fish or both. One participant was saddened and tearful when she first saw the photograph she had taken of one of her dogs because she had recently had to put the dog to sleep (Figure 13). She described their companionship and the positive impact the pet had on her health and in her life by saying:

Oh my gosh, I’m trying not to cry, we just had to put her to sleep the other day. And I’m so glad I just got this picture. Sorry…but yeah my strengths [tearful]. Yeah, that’s my baby, my baby…..she was the oldest. I had her for years, yeah…but um….they’re my strengths and yeah [tearful] they motivate me. They uh, if I’m laying around, they’ll pick me up…they know something’s wrong…yeah…they I don’t know they’re just like kids…they don’t talk, but if something’s wrong or…uh…mainly when something’s wrong, they’ll come up to you, they make you play. Yeah. [crying] (Participant 2, Interview 2)
Others described the animals as members of their family and conveyed how the animals helped to provide joy, decreased stress levels and offered opportunities for physical exercise.

4.8.2.2.4 Physical Environment

The participant’s photographed several outdoor scenes or paintings/prints of outdoor scenes and described the numerous ways that their physical environment and nature positively impacted their health. Wooded areas, parks, waterfalls, walking trails and participant’s backyards were among the many photographs taken by the participants. They explained that their physical environments and nature offered them opportunities for relaxation, reflection, exercising and recreating.
A number of the participants described the ways in which their surrounding physical environment provided them a chance to relax and reflect on their life circumstances. They used descriptions like “getaway oasis,” “peaceful,” “cleansing,” and “relaxing” to describe these areas and the positive effects on their mental and physical health. Participants also reported that the natural environment prompted them to reflect on their life circumstances. For example, one participant reflected on a photograph of the woods in her backyard saying that it prompted to think about her journey with HIV (Figure 14). She described the photograph in the following way:

The outdoors, the uh…wildlife…it’s a big strength too it’s just…it’s like it’s just so soothing. And I look at the, an it’s like, actually my backyard and it’s like, a couple months ago about two months ago it was nothing green…I could see straight through the, the, the to the next street to the other houses. Just dead…that’s the word I’m trying to use. Now all of a sudden it’s alive! And I’m like ‘gosh’ oh nature is just…it reminds me it’s like…like I was dead [laughs] like my body was dead….I was just….now I’m alive again! … It was alive and I felt like dang I was dead once, not physically but just sort of mind, mentally I was like…I was dead. But now I’m alive and I done bloomed back out. (Participant 2, Interview 2)
Another participant photographed a similar scene and noted that living with HIV had heightened her appreciation for the outdoors (Figure 15). She explained:

Yeah, it was just nature. Something I can still enjoy…Well I kind of started appreciating it more after knowing you know I was diagnosed I kind of appreciate a lot of things more and nature was one of- flowers, trees, the sky.

(Participant 009, Interview 2)
In addition to the mental and emotional benefits of their physical environments, participants also conveyed its importance for their physical health. They photographed the walking trails and parks where they enjoyed recreating and exercising. One participant took a photograph of her front yard and detailed the many opportunities it provided for physical exercise (Figure 16). She stated:

I see a big yard with- I love playing in leaves. (laugh) I just love leaves. Um, this is where I play with my dog at sometimes and- it's not a concern I think it's more of a- um, a strength. Cause I like this, I rakes the yard, I love to cut grass. It makes- mainly my legs I get concerned about. ‘Cause I got an enlarged heart so I have to you know what I'm saying? Do things to keep me- everything level. So this yard right here is big enough for me- by the time I do this yard- I've got a blower, but I really rake it. You know what I'm saying? It builds my muscles in my bones. Cause I'm not doing too much lifting or nothing like that, then my bones get weak. So it mainly helps me health-wise, stay in shape (Participant 012, Interview 2).
Relaxation, reflection, exercise and recreating were all positive health benefits identified by the participants as they photographed and described their physical environments.

4.8.2.2.5 Transportation

The transportation means utilized by participants varied (private vehicles v. public transport such as buses and medical transport van services) along with the health benefits and deficits they associated with each suggested transportation was an important social determinant of health. Some participants described the positive aspects of their private vehicles such as independence and reliability in accessing health care services, while other participants described the financial and mental stress of maintaining their vehicles or using public transportation. For example, one participant
had acquired a car when while participating in the study (Figure 17) and she excitedly described the benefits of her new transportation and no longer having to take medical transportation in this way:

Some days, they didn’t even pick me up you know even though I called in and I had the appointment so some days they didn’t even show up because they was too booked, too busy and they were just way behind. So I just missed that appointment and had to reschedule. So that kind of, that was like towards the end before I got the car because I was just getting fed up with them. And I was like ‘oh I can’t wait to get a car’ and finally got a car. So I don’t have to deal with that anymore (Participant 003, Interview 2)

Another participant also identified her car as a social determinant of health (Figure 18) but focused on the negative aspects of attempting to maintain a private vehicle on a limited income and the tradeoffs of living in a place where one needs a private vehicle for transportation versus public transportation:
That’s my mode of transportation. And that’s important to me because that gets me to my appointments, it gets me to pick up my kids, it gets me to where I need to go. Um, it’s also a concern. Because you have to keep it up. Keep up the maintenance. And keep it up and that’s not easy to do. Um, so you know, and being on a fixed income, and having car issues it’s like shoo! … I’m always concerned about, is this car going to last me a couple of years-I say that all the time, so it’s a concern. We could have better transportation, you know, public transportation could be a lot better. Like the nearest bus stop to my house is like back all the way down [street name] by the apartments, like, all the way over! Yeah so then like you’re forced to move and if you don’t have a car you’re forced to move somewhere that the bus is you know, and you may not want to do that. And I feel like with this disease you need peace, you need peace and quiet and serenity and you know you don’t need to be worried about somebody busting in on your house you know? (Participant 004, Interview 2)

Figure 18: Transportation Photograph 2

As noted by this participant, public transportation was generally described by participants as unreliable, inaccessible or inconvenient; in other words, a negative social determinant of health. Another participant described her experience with using the bus
system (Figure 19) while she was recovering from a major hip surgery and using a walker. She stated:

So…the bus system in [city] is crazy… ‘Cause you have to meet-in [a different state] you normally cut through, if I wanted to [hospital] get on the bus here, then turn two blocks down get on another bus, but you have to all go to this one place which is downtown then get another bus and it’s spread out. And if you have to go somewhere else there is no connection. You have to come back downtown and then go again… it’s time consuming. (Participant 001, Interview 2)

Figure 19: Transportation Photograph 3

While private transportation was the mode preferred by participants over public transportation, it was also financially inaccessible to many. One participant went so far
as to photograph (Figure 20) the vehicle she wished (but failed) to purchase as she was caring for her ailing husband. She described her dashed hope in this way:

This is the car I was trying to buy okay- okay while my husband was in the hospital …’Cause I really want it you know for transportation for my husband just so I can bring him back and forth to the doctor’s appointments and things like that. (Participant 019, Interview 2)

![Transportation Photograph 4](image)

Figure 20: Transportation Photograph 4

The participants identified both positive and negative aspects of the various forms of transportation and the associated health implications; yet, reliability, accessibility and affordability clearly emerged as the most important qualities of any of the modes of transportation noted.

### 4.8.2.6 Housing

Of all the social determinants of health, housing was the most tenuous as described by participants in the photo elicitation data. Although I did not specifically
ask the participants about their housing situations, one (1) participant reported a previously unsafe housing situation, two (2) participants reported previous homelessness, one (1) participant was lost to follow up due to homelessness and one (1) participant and her children were residing in a homeless shelter while she was enrolled in the study. As such, participants described their housing situations as extremely important in maintaining their health status. For example, one participant took a photograph of the hallway in her apartment (Figure 21), described her home as a positive social determinant of health and relayed a story about her recent experience of illness, and subsequent unemployment and homelessness. Through this story she explained the importance of a stable housing situation and its positive health implications:

It keeps me sane. It keeps me sane. If I know I have home to go home to and not... like we stayed at a hotel for a couple of months. Then we did the shelter. It’s not- the hotel might have a little bit more privacy but it wasn’t safe for me for the kids. But it was a lot more I should say a little more privacy. In the shelter even though we had our own room our doors couldn’t be locked. And I always had the fear of someone coming into my room. I didn’t care about the other possessions but like finding a bottle of my medication. You know, stuff like that. And anyone can hop up on Google and put in a medication name and it’ll tell them what it’s for. And then being stigmatized for that. So that was like one of my biggest fears being in the shelter. (Participant 11, Interview 2)
Another participant reported extreme gratitude for the assistance she received in acquiring an apartment for herself and her family through a state voucher program (Figure 22). When asked how her current housing situation impacted her health, she seemed to be laughing at the absurdity of the question when she responded:

[laughs] Um....that impacts a great deal. Because if I was homeless um, of course, wouldn’t have pretty much access to water, wouldn’t be able to feed myself, to cook in my own kitchen rather... I can’t say I’ve never been homeless because I know that part of the fence and I know having your own part of the fence so you know I’m just really grateful. (Participant 003, Interview 2)
Housing was certainly portrayed as a positive social determinant of health by the participants, although they also clearly depicted its tenuous nature for those living in poverty.

4.8.2.3 Content Analysis of Storyline Graph and Participant Trajectories

Here, I present the findings from the storyline graphs generated with 11 of the 18 participants. Those participants not included were either enrolled prior to the inclusion of this data collection procedure in the research protocol (i.e., pilot study participants) or the interview did not generate sufficient information to complete the graph. The goal of the section is to bring light to the temporal aspects of social location and identify patterns in the participants’ trajectories of motherhood while living with HIV. I
highlight two primary findings using the participant’s descriptions of the key moments in their life trajectories of living with HIV and motherhood, contextual data from the interviews and field notes to construct the graphs. One, the pattern of emotional response toward their HIV diagnosis universally moved in a positive direction over time. Two, being diagnosed with HIV during pregnancy appears to be a particularly emotionally vulnerable time for participants resulting in both cognitive and emotional dissonance. All eleven of the participant storyline graphs and exemplar quotes can be found in Appendix H.

4.8.2.3.1 Time Heals

Without exception, participants described their trajectory of living with HIV as moving in a positive emotional direction over time. Even those who described having HIV as a negative emotional experience at the time of the interview described it more positively than when they were first diagnosed. For example, Participant 012 described her emotional response to her HIV diagnosis at age 24 by saying, “I was suicidal” (Participant 012, Interview 1). Although the change was subtle, by the age of 55 this particular participant was no longer in serious emotional crisis, was actively seeking physical and emotional care for her condition, and acted as a peer counselor for other people living with HIV. Her storyline graph and exemplar quotes are depicted below (Figure 23).
Other participants had far more positive dramatic shifts in their emotional responses to living with HIV over time. Like Participant 012, Participant 013 also had a very negative initial emotional response to the diagnosis with HIV at the age of 23 years. She too reported being suicidal when she was diagnosed and stated, “I didn’t want to live. I really didn’t” (Participant 013, Interview 1). By the age of 30 years, she articulated, “You know it’s only been about a few years ago but you know I started saying it’s a
reason to live...I am living life to the fullest, that’s what I’m doing” (Participant 013, Interview 2). Her storyline graph and exemplar quotes are depicted below (Figure 24).

![Storyline Graph: Participant 013](image)

20 yo - Delivered 1st child; did not assign emotional value
23 yo - Diagnosed with HIV during a pregnancy that she ultimately miscarried; stated ”I didn’t want to live, I really didn’t” (Interview 1)
28 yo - Delivered 2nd child; stated "I didn’t want to be pregnant with him..." (Interview 2)
29 yo - Delivered 3rd child; stated she "was not ready for another baby" (Interview 1)
30 yo - reported recent positive events and feeling proud of her oldest daughter (track and field and cheerleading); also reported excitement when her second child recently started walking, described her two youngest children as "miracle babies" for being HIV negative (Interview 1) Current perception of motherhood stated, "It might be hard but I think we live for our little ones." (Interview 3)
30 yo - Current perception of living with HIV, stated "So I say- you know it’s only been about a few years ago but you know I started saying, ‘It’s a reason to live. And like I said, there’s a reason for everything. There is a reason why I’m still here. So I just look at it like- I’m living life to the fullest, that’s what I’m doing. ” (Interview 2)

**Figure 24: Storyline Graph Participant 013**

Although the participants’ storyline trajectories of living with HIV varied in their degree of emotional response, they generally reflected some sense of emotional
healing over time.

| 4.8.2.3.2 Cognitive & Emotional Dissonance |

The cognitive and emotional dissonance described by participants who simultaneously received their diagnosis of HIV with pregnancy appeared to create a particularly vulnerable emotional situation. Four of the eleven participants with storyline graphs reported that they simultaneously learned they were HIV infected and pregnant. These participants described feeling deeply conflicted with emotions of both joy for the pregnancy and sadness regarding their HIV diagnosis. One participant stated, “it was devastating…it was a blessing to have him but…finding out all at one time it’s like overwhelming.” (Participant 016, Interview, 1). Another participant echoed these sentiments and stated that she felt like she just “couldn’t live anymore…” when she was diagnosed, but that she was “happy and sad at the same time because [she] found out [she] was positive…” (Participant 018, Interview 1) The participants described this cognitive dissonance between the normality of motherhood and deviance of HIV infection (Sandelowski & Barroso, 2003) as making it very difficult for them to cope with either of the situations, the pregnancy or the HIV infection.

| 4.8.2.4 Content Analysis of Intersecting Social Determinants of Health |

The participants’ descriptions of their intersecting social determinants and their concurrent impact on their health experiences as represented by three categories:
mutually constituted strengths, mutually constituted vulnerabilities or as opposing determinants.

The participants described their social determinants in such a way that demonstrated how social determinants intersect to concurrently impact their health as mutually constituted strengths, mutually constituted vulnerabilities or as opposing determinants (Appendix I). The goal of this section is to show the ways in which the participants conceptualize and describe the co-occurrence of social determinants and their subsequent impact on health experiences. The output from the code co-occurrence tool in Atlast.ti (Atlas.ti, 2015) was used as a starting point in determining and describing these intersections of social determinants of health.

4.8.2.4.1 Mutually Constituted Strengths

One participant described social determinants that intersected to elicit an overall positive health response or how they worked concurrently to impact her health in a positive way. When she was asked to describe the ways, if any, she felt being a woman impacted her experience of living with HIV, she responded:

I don’t know if I can really answer that because…being a woman with HIV for me I would say it’s different because I’m a mother. So…I guess it impacts me as far as my children and the concern and stuff like that um, so I would say yeah it’s difference for me you know, as far as the aspect of being a mom and trying to raise the children that I have…[being a mother] makes it different because it makes you want to take care of yourself even more, to be here for your children, to school them, about this disease…So you know just being a mom and trying to be here for my children makes it better for me. (Participant 003, Interview 3)
Of the multiple determinants identified in the conceptual model, only motherhood and gender intersected in this way and only one participant described this intersection. None of the other determinants co-occurred in such a manner that participants described them as a mutually constituted strengths.

### 4.8.2.4.2 Mutually Constituted Vulnerabilities

Participants described social determinants that intersected to elicit an overall negative health response or that worked concurrently to impact their health in negative ways. The majority of the intersections represented in the data were in this category and they were both bi-dimensional and multidimensional in nature. One participant offered an answer demonstrating a bi-dimensional intersection of social determinants, when asked in what ways, if any, being a woman impacts her ability to take care of her HIV:

> Taking care of kids, having kids, having children running around and working...’Cause I know for me, for years I like I got to work, I got to work and put my doctor’s appointments to the sides because I had to go. And I rescheduled, I rescheduled, I rescheduled. And then it becomes a-, after you’re done reschedules it’s like yeah forget about it-I’m feeling fine…” (Participant 001, Interview 3)

This participant moves from a description of being a woman to her role of being a mother and how that impacts her health. It is as though, for her, motherhood is an implicit part of being a woman. In this way, her gender and motherhood intersect in
such a way to negatively impact her ability to make and attend her health appointments.

Other participants gave descriptions of how multiple social determinants simultaneously intersect in negative ways. For example, one participant described the multidimensional intersection of race, class and motherhood when asked what it is like being an African American mother:

Um well, it is a struggle. Um for one thing it is a lot of still a lot of prejudice going on, ever though sometimes it’s not as visible as it used to be. Um even in politics today, this man that’s running against Obama you can tell he’s not for the poor and the um midclass families. He’s only for the rich because he wants to cut out everything for the poor folks, well for the middle class families...And looking at that itself is really a struggle ‘cause you’re having to, as my grandmother would say ‘you had to steal from Paul in order to pay Peter.’...and you may not have to do it all the times, but you, you try to figure out ways that you can cut back on certain things so you can, the little money that you do have, you can stretch it out. And not only with that in case any activity, say anything come up for the children you sho’ enough you got to rob Paul to pay Peter in order to look out for them. (Participant 006, Interview 3).

In this case, the participant described the invisible nature of the prejudice she experiences being African American and then moves directly to her race being associated with the middle to lower socioeconomic classes. Again, it is as though the participant has identified one determinant as implicit with another and in this case she seemed to view her class as implicit with her race. She then described how each of these, race and class, are connected to the struggles in meeting the needs of her children. Ultimately, later in the interview, this participant identifies her class as the
social determinant most detrimental to her caring for her health and HIV.

Another participant described the multidimensional and negative intersection of race, gender and HIV-related stigma when she offered:

I don’t know, it’s like a lot of people…for a black woman, to me, they find out you’re HIV or AIDS, you’ve got to be, you’ve got to have been a prostitute. Or you had to sell your body or you’re considered a little bit like nasty. Yes. …a couple of years ago I was in a class, I mean, when I was first diagnosed I did a lot of classes and a lot of studies and things of this nature and…and um I was in a class after the class and a lady no a man, my fault, a man had the nerve to ask me he said ‘did you sleep with a lot of people?’ and I was like….no. And it sort of threw me for a loop and um…I was like… ‘no why would you say that’ and he was like ‘well most black women with HIV I consider they’d slept with a lot of men’ as in you know prostituting or selling their body or stuff. I was like ‘no not in this case...’ you know, and it took me for a loop you know…That’s why you know like I said, my last interview before that was like...you just can’t let everybody know, it’s not that I’m ashamed of this but there’s a lot of cruelty out there you know? (Participant 2, Interview 3)

This participant went on to describe that such experiences have frequently hurt her feelings but she denied they had ever stopped her from accessing treatment. So, while the mutually constituted vulnerabilities of race, gender and stigma have not impacted her access to care, she reported significant psychosocial health implications.

4.8.2.4.3 Opposing Determinants

Participants described that, at times, social determinants intersected in such a way as to oppose one another. In other words, while one determinant might be negatively impacting her health, another determinant might be acting as an opposing positive force. One participant described how motherhood acts as an opposing health
determinant in her life against the HIV-related stigma and racism that she experiences:

I think that’s—as matter of fact I know that’s why I’ve made it this far, because I don’t think if it was for them, I probably would have given up a long time ago. I have those days I’m just like I don’t want to do this I’m tired. But I have to remember my children so you know…that to me is a blessing and I look at it as if God knew, he knew that I would need that kind of motivation because if I did not have my children I’d probably just lay down in a corner somewhere just like leave me alone, let me die. I mean just because I think it is the medicine, society, you know some people will say ‘oh you’re not limited in what you can do if you’re HIV positive.’ There are always going to be limitations until the thinking, until the mind change, until um…until there’s an actual change in humanity and our mindsets it’s going to always be an issue and a problem…you know. And unless you move to you know you just have this utopia where everybody loves everybody and everybody gets along, no one sees color no one sees anything they don’t see you know shortcomings and you know, and we’re not there, so…there’s you know what you I think that’s just…part of life and you know, and we deal but I think it’s just so much harder especially not in my community. (Participant 4, Interview 1)

In addition, only one participant described the intersection all five of the social determinants (i.e. gender-, race- and class – inequality; HIV-related stigma; and motherhood) in a single response. The participant explained her efforts to access services from local health/social service agencies and described the following:

I think just dealing with the ignorance and the stigma in the African American community I think it hinders me. Every time I go to the clinic I’m like ‘oh God…I hate walking this wall, people so nosey in this hospital’…And then even with [different organization] I’m like, these places are here to help people but for me, “ I’ve had bad experiences there….I just feel like we categorize people sometimes, especially, especially African American women are often categorized. Like at the end of the day if you want to take care of yourself and you want to look like something then they feel like ‘oh yeah you’ve got this, you’ve got, no!’ No I don’t have! No my bank account says zero it’s just I refuse
to look like I’m tore down and broke down like why do I have to look like that! Who says I have to look like that? I don’t have to look like that. I chose not to look like that. And I choose for my children not to look like that. They don’t have to look like we just came out of the dirt, a hut or something, what! No, mm-mm, no. I just think I’m not going to go any place just looking broke down for you to help me. This is who I am, either you’re going to help me based off the fact that I need the help, and I meet the criteria or you’re going to make it hard for me. (Participant 004, Interview 1)

In this response, the social determinants of racism, gender-inequality, class-inequality and HIV-related stigma are all negatively impacting her health experience but she described her effort to counter them through her role as a mother and caring for her children. Without exception, motherhood was the only social determinant described by participants as exerting a positive influence against the other determinants outlined in the conceptual model. Contrary to a conclusion that motherhood is the only social determinant positively impacting the health of these women, is that it might be the only social determinant positively impacting the health of these women that was included in the model. Throughout the interviews participants described other positive social determinants of health that were not included in the model. The inter-relationship of all five determinants (race-, class-, gender- inequality, motherhood and HIV-related stigma) was also not fully described using this single approach to the data because it was difficult to ask questions that elicited responses that included all five of the determinants. As such, a second analytic approach using vector models was used for visualization and theoretical purposes.
4.8.2 Phase Two: Vector Analysis

Vector analysis was used for conceptualizing and visualizing the configuration of a participant’s intersecting social determinants as they related to her overall self-health assessment. Vector analyses were completed for fourteen (14) participants (Appendices J – W). The remaining four cases did not include complete data sets to allow for vector analysis. For each case, I used the force and valence (positive or negative) of each social determinant from the conceptual model (i.e. gender-, race- and class – inequality; HIV-related stigma; and motherhood), contextual data from the interviews and field notes, and the participant’s self-assessment of their health. In this section of the findings, I present three exemplar individual vector models beginning with a summary description of the participant’s case followed by a description of the participant’s perceptions of their social determinants of health and overall self-health assessment. Figures 29, 35 & 39 are graphic figures of the exemplar vector models.

4.8.2.1 Vector Model Participant 006

4.8.2.1.1 Case description Participant 006: “We all try to stay positive”

When I met Participant 006, she was living in an urban area of the Research Triangle of North Carolina. I will call her Rose. All three of Rose’s interviews took place in a private room at the Duke University School of Nursing and at the time of enrollment, she was 53 years old. Rose was single, lived with her mother and had
recently (within the past year) become the guardian for her niece and nephew, ages 12 and 10 years, respectively. The children’s mother, Rose’s sister, had been institutionalized as the result of drug addiction.

I chose to call this case “we all try to stay positive” because Rose used these words as she described her families’ new circumstances and the recent guardianship of her niece and nephew. During the interview, Rose frequently reframed her life circumstances by saying that she tried to stay positive no matter the circumstance and this was evident as she described her course with HIV.

Like her sister, Rose had also struggled with drug addiction and did not address her HIV for many years. She reported being diagnosed the first time in 1991 while in jail and she stated that at the time "I didn’t really give a damn" (Interview 1). She reported that in 2004, she was jailed again, diagnosed a second time, and began treatment with her local health department. The HIV diagnosis in 2004 is the time frame she reported on the demographic form. Rose reported that she did not feel any different, better or worse, since being on treatment, although she spontaneously reported knowing it was better for her to take her medications and that she did so consistently (Interview 1). With regards to her HIV infection she stated:

But positive note with HIV I’ve learned that as long as I take my meds and take them like I’m supposed to, I shouldn’t have any complications, as long as I’m having protected sex and like I said basically doing what I’m supposed to do, I shouldn’t have any worries and right now in my life I don’t. Because I can
honestly say that I’m okay.” (Interview 1)

Interestingly, Rose also stated the following with regards to her HIV infection that she had “… heard it plenty of places that if you don’t claim it, you ain’t got it.” (Interview 1)

Rose had not disclosed her HIV status to her mother or her dependent children. During the informed consent process, however, Rose did grant permission for the photographs to be used for research presentations and publications.

The vast majority of Rose’s photographs focused on positive social determinants of health such as her physical environment, the relationships she has with the children in her life and her church community. Rose took several pictures (e.g. Figure 25) from what she described as a “fun day” at a local recreation area with the children she babysits and remarked several times about the beauty of the environment.

Figure 25: Rose, Photograph 1
Rose also portrayed the relationships she has with the children she babysits, the children she teaches in Bible study and of course, her niece and nephew. She seemed to view her role with these children primarily as one in which she instills lessons and imparts knowledge. She took a photograph (Figure 26) of the school supplies she had bought for the children in her Bible study class and stated “And like I said, it was a positive thing for me. A good strength ‘cause it keeps me focused on the younger generation. How to teach them, you know?” (Interview 2)

![Figure 26: Rose, Photograph 2](image)

Rose frequently referred to her church and to religion (Figure 27). She reported relying on her church for spiritual support, social support, and as a means for serving others. When asked how church related to her health she stated:

It’s been a big positive. Nobody in the church knows [that she is HIV positive] but I’m the type person where you know they have a saying ‘get in where you
fit in.’ That’s a street saying but anyway, anywhere I see that I can do something positive for me because I’m actually volunteering to do it. I jump right in there and do it. (Interview 2)

Figure 27: Rose, Photograph 3

Rose referred to her housing as a “mixed” health determinant, having both negative and positive qualities. Her mother owns the home in her photograph (Figure 28) and she describes it as a positive (strength) in her life because it was a place for she and her family to live and the neighborhood was quiet. She also noted that it was a concern because she realizes that if something happens to her elderly mother they will likely not be able to afford it. Once again, however, Rose reframed this situation and stated "...but I’m hoping and praying things going to get better and they are, so we’re going to worry about that when it comes. It’s going to get better. Yep." (Interview 2)
Rose described her new role as a mother to her niece and nephew in almost exclusively positive terms. She spent a large portion of her interviews detailing how she was raising her niece and nephew. She proudly provided story after story of how she was instructing them and disciplining them.

Rose also articulated a strong desire to raise her niece and nephew in a church community and she thanked her mother for instilling that desire in her. Rose's feeling about being the guardian of her niece and nephew seemed to change over time. She described that in the beginning "I didn't want to accept it but had to..." (Interview 1). Throughout the rest of the interviews, however, she reframed the situation and spoke
positively about the arrangement. Rose appeared to do a great deal of cognitive reframing during her interviews. Often she reframed her situation in the context of her religious/spiritual beliefs but sometimes she did not. For example, when talking about her relationship with the children she said, "Everything is on the positive mode. I try to keep it that way, you know?" (Interview 2) At the end of the third interview, Rose identified motherhood as the most important positive health determinant in her life. This is somewhat surprising as it is a relatively new role for Rose, although she described informally parenting her niece, nephew and the children from her church for many years. Motherhood (~M) is reflected as a vector exerting force in a positive direction from the health experience plane.

Race/racism and HIV-related stigma were coded as non-determinants on Rose’s health experience plane. Rose reported there is "still a lot of prejudice going on even though sometimes it’s not as visible as it used to be." (Interview 3) She does not suggest at any point, however, that racism or being African American has negatively or positively impacted her or her health. When asked about HIV-related stigma, she moved away from the question and reported that most people do not know about her HIV status. From Rose’s vantage point, it seemed that if people do not know about her status, then it is not an issue. When asked about all the determinants in the conceptual model, Rose stated, “...But other than that, the other four reasons, I basically just don’t
even try to put far as my race being a issue. Being a woman is not a issue. What other people will say is not an issue..." (Interview 3)

Gender was coded slightly differently than race and HIV-related stigma for Rose because despite her exclamation above that being a women was not a health determinant, Rose did report positive health aspects of being female. She expressed that she felt women were more "adept" at caring for themselves and their health. As such, gender is (~G) is reflected as a vector exerting force in a positive direction from the health experience plane.

Rose reported the most difficult part of her new mothering role was the financial aspect and also identified her financial status (class) as the social determinant most negatively impacting her health. She reported that it particularly impacts their ability to access healthful foods and do the activities they wish to do. She was not concerned about it impacting her healthcare access and reported that she has good health coverage and free medications from ADAP. Nonetheless, class (C) is reflected as a vector exerting force in a negative direction from the health experience plane.

4.8.2.2.3 Self-assessment of Health: Rose

Rose's definition of health seemed to be one of health maintenance and prevention and she reported that she was healthy based on this definition. She stated "Yes. ‘Cause I’m doing what I’m suppose to do, like I should do"(Interview 3).
Therefore, the health self-assessment vector (+) is reflected as exerting force in a positive direction from the health experience plane.

Figure 29: Vector Model – Rose

4.8.2.2 Vector Model Participant 016

4.8.2.2.1 Case description Participant 016: “We don’t get sick days”

When I met Participant 016, she was residing in an apartment in an urban community in the Research Triangle of North Carolina and this was the location of all three of her interviews. I will call her Camille. At the time of enrollment, Camille was a 31 year-old African American woman and she lived with her only child, a 10-year old son. The father of her child was not involved in their lives, but Camille reported that she currently had a partner. Camille was diagnosed with HIV ten (10) years prior to
enrollment in the study during her pregnancy with her son. I chose to call this case "We don’t get sick days" because Camille jokingly referred to this line from a television commercial and it reflected the difficulty she perceived in being a mother living with HIV. With regards to her current perception of living with HIV, Camille remarked, "I feel like I am surviving...so I feel like motivated, like I gotta do- I gotta enjoy life...don't let it get to me." (Interview 1). In this statement, Camille’s decision to enjoy life seemed more like a personal mandate rather than a choice, but she seemed to have positively reframed her situation nonetheless. Camille frequently reframed her life circumstances in a positive manner and she attributed this partly due to her faith in God and partly because of the social support she receives from her parents, boyfriend and church community. Camille admitted, however, that recently she was asked by her healthcare provider to begin anti-retroviral therapy and that had been difficult milestone for her. Camille reported the following:

   It was hard at first I was like, 'I wow, I gotta take these big pills.' And the suspense-so I had to go through a lot to get it. I had to go through a program to get the medication. My medicine is high, so that was my mind-boggling. So I had to really fight for a month, just to get my medication. It was, to me it’s a lot of work. You get what I’m saying? (Interview 1)

Camille had disclosed her HIV status to her partner and immediate family, but not to her son. He was at school during each of the interviews. She stated that she had not disclosed to him because she felt like he would be “heartbroken” and "he [has] got
enough to worry about being a Black male and just trying to make it” (Interview 3). She went on to say that she worried about him "...being judged, being a statistic” (Interview 3) as a Black male. Camille granted permission for her photographs to be used in research presentations and publication during the informed consent process.

For the most part, Camille took photographs that focused on the positive health determinants in her life (9 out of 12 photos), although she was very open about the fact that things are not always positive for her. Three (3) photographs in particular revealed her sentiment - a toy, a light switch and a clock. Camille reflected on the photograph of a toy (Figure 30) that tells that story of the Old Lady and the Shoe and she stated, “Sometimes I feel like an old woman that lives in a shoe. Sometimes I feel like I’m trapped” (Interview 2). She went on to say that it was her HIV infection that caused her to feel trapped and made it hard for her to feel positive.

Figure 30: Camille, Photograph 1

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In the picture of the light switch (Figure 31), one of the three switches was down and the other two were up or on. She likened this to how she feels - sometimes good (or on) and sometimes bad (off). When asked how the photograph related to her health, she stated:

So it's like you know, sometimes you feel like giving up but you know you can't. So that's why I put the light switches down. Like sometimes like I feel down. Sometimes I feel up, I mean I'm human though so that's how I feel like that. It can be a concern but to me it's not really a concern it's really a strength because I know I gotta do- is stay up. (Interview 2)

Again this seemed a bit more like a personal mandate than a choice, but she chose to focus on the positive.

Figure 31: Camille, Photograph 2

Many of the photographs Camille took represented positive social determinants of health such as her strong social support network, her faith in God, and her son. In
reference to a photograph of a painting of a house (Figure 32), she expressed that she was raised in a house and that she believed it represented the stability of family.

Camille reported that her family related to her health because:

…basically a family can help you keep your mind off- help you um, if you feel like you need to talk to someone or you feel like you could be depressed or whatever- you can talk to someone. (Interview 2)

Figure 32: Camille, Photograph 3

When asked about a photograph of a plaque of The Serenity Prayer (Figure 33), Camille reported that prayer impacted her health in the following way:

It gives me focus, prayer changes things. It keeps me you know- comfort, it keeps my focused. It keeps me in belief. You know what I’m saying it keeps your focus on God you know God will carry you through…Cause it gives me the ah, the belief that I know I can do, I can overcome this. I don’t let it get me under and depressed. And I just pray and I pray that God will keep my body, keep my immune system strong, my CD4 count you know like they’re supposed to. I know prayer changes- it keeps me together. (Interview 2)
Figure 33: Camille, Photograph 4

Camille also photographed other religious symbols such as her Bible and a guardian angel figurine.

| 4.8.2.2.2 Social Determinants of Health: Camille |

Camille described motherhood as the primary motivator for caring for her health. Throughout the interviews, she consistently referred to the positive nature of her relationship with her son and the important ways their relationship impacted her health. She described her son as “…a loving child. I feel like God gave me a blessing and I have to take care of him. He makes me happy, just being a parent, just being his mom” (Interview 1). Camille reported that she enjoyed teaching him things like cooking, budgeting and making good decisions. Figure 34 is a photograph of a Nascar
book that Camille described as representing her son because he likes racecars.

![Camille, Photograph 5](image)

**Figure 34: Camille, Photograph 5**

She described how motherhood impacted her health in the following way:

‘Cause I know I have to take care of myself cause I have to live for someone- live for someone else like I have to be there regardless. So I have to take care of myself, to keep going on, to be all I can for him. I got to keep my health together. (Interview 1)

Motherhood serves as a motivation for Camille to care for her health and she also described it as the social determinant most positively impacting her health, so Motherhood (~M) is reflected as a vector exerting force in a positive direction from the health experience plane.

Camille spoke about her race, class and gender from an intersectional perspective on a couple of occasions. In other words, she viewed these determinants as mutually constituted and she spoke about them concurrently as she described her
social location. For example, when asked what it was like being an African American mother, Camille hesitated because she did not want to offend me, but ultimately responded:

It’s hard…’Cause you feel like oh no, I don’t want to be offensive. You sure you won’t take it like that? ‘Cause I feel like being Black it’s hard already, that’s already one strike and I’m a woman, that’s a second. So that’s a lot it’s like you got to fight your way all the way through…Yeah, you have to fight to keep your place. You got to keep your car. You have to, you know, work and you have to do everything you can just to keep everything. Sometimes you got to take jobs you don’t want to do. (P laughs) (Interview 3)

When asked about each determinant specifically, however, Camille elaborated. She reported that she had experienced racism and gave the example of being called a “N—-” in a predominantly white, affluent community (Interview 3). Race (R) is reflected as a vector exerting force in a negative direction from the health experience plane.

Camille identified her financial circumstance and socioeconomic class as negatively impacting her health, although she reported having access to healthcare. In fact, she went so far as to laughingly say, “Bills can make you sick” (Interview 3). She also described an interesting intersection between race and classism in which she felt judged both inside and outside of her racial community. She stated:

Okay, yeah, mostly White people in [name of town], so people look at you like that. Even sometimes your own- my own color look at you like that….’cause you not making the money that they making. (Interview 3)

Indeed, in the third interview, Camille identified class as the social determinant most
negatively impacting her health; therefore, class (C) is reflected as a vector exerting force in a negative direction from the health experience plane.

Camille denied that she had experienced gender discrimination as a woman living with HIV, but she reported that her gender does impact her health. She stated, “It's a lot; you know we take in things emotionally so it's always hard, everything is hard so you got to try to do everything just to take care of yourself” (Interview 3). As stated earlier, Camille also described being a woman as a “strike” against her. As such, gender (G) is reflected as a vector exerting force in a negative direction from the health experience plane.

The final social determinant of health in the model, HIV-related stigma, was a non-determinant to Camille, largely because she had not disclosed her HIV status to many people. As she reflected on HIV-related stigma she stated, “- me having HIV who knows if I don’t tell? You know what I'm saying?” (Interview 3) She felt that she was treated the same as others and stated that there was “no difference” (Interview 3). Camille attributed nothing positive or negative to HIV-related stigma; therefore, it is not reflected on the health experience plane and was coded as a non-determinant.

| 4.8.2.2.3 Self-assessment of Health: Camille |

When asked to define health in her own words, Camille gave the following definition:
Um, oh that’s a good question. I guess to take care of yourself, in a nutshell- take care of yourself. Get your exams and take your medication, do you appointments, do your physicals, do everything to fight to live, okay. If you don’t take care of yourself or you don’t diagnose the problem you’ve become sick and you’ve- you know what I’m saying and you become worse than what you are now. So health is to take care of yourself, do all you can (Interview 3).

Camille’s answer seemed to suggest that health was about the effort to care for oneself and when asked if she considered herself healthy based on her own definition, she responded, “I consider- the best that I can. I think I consider myself- like I do all I can” (Interview 3). Therefore, the health self-assessment vector (+) is reflected as exerting force in a positive direction from the health experience plane.

Figure 35: Vector Model – Camille
4.8.2.3 Vector Model Participant 012

| 4.8.2.3.1 Case Description of Participant 012: “I don’t know why I’m still alive” |

When I met Participant 012, she was residing in a home in an urban community in the Research Triangle of North Carolina and this was the location of all three of her interviews. I will call her Ophelia. At the time of enrollment, Ophelia was a 54-year old African American woman with two adult children, ages 38 and 37 years, as well as grandchildren and great grandchildren. Ophelia reported two dependents, her eight (8) and fifteen (15) year old grandchildren. Ophelia reported being married, but did not live with her husband and had been living with HIV for thirty-one (31) years.

I chose to call this case “I don’t know why I’m still alive” because during her first interview Ophelia made this statement and she continued to reflect on her difficult life circumstances during each of the interviews. In doing so, Ophelia gave a very interesting historical perspective on her experience of living with HIV, as she was diagnosed very early in the epidemic. She recalled that when she was diagnosed, the local newspaper posted on the front page of the paper the names of sixty-four (64) people thought be infected with HIV. She described feeling “suicidal” at the time (Interview 1) and lamented that she believes only eight (8) of those people are still living. Ophelia also recounted how she felt she had "killed" her partner from that time period because he also became infected with the virus and ultimately died (Interview
1). Ophelia seemed to harbor a great deal of sorrow and guilt about these situations and was visibly disturbed and crying when she relayed the stories. Her current perception of living with HIV was also rather bleak and when asked about how she presently felt about her HIV and her health began to cry and stated:

Well ah- I know I can't get rid of it. (P crying) It ain't my fault. That’s the question I keep asking God, 'What did I do so wrong to get this-that this happened to me?’ But I’m living with it. I’m living with it. I get so frustrated cause sometimes I forget I ain't normal...(Interview 1).

Ophelia had disclosed her HIV status to her immediate family and she granted permission for her photographs to be used in research presentations and publication during the informed consent process.

In the photo elicitation interview, Ophelia identified many of the social determinants of health she represented in her photographs as being both positive and negative or dual in nature. She would describe a positive aspect of certain determinant and then qualify her statement with a negative statement. She identified her relationship with her grandchildren, her housing, television, and her eating habits all as both positively and negatively impacting her health. For example, Ophelia described her home (Figure 36) by first saying, "...I feel peaceful and God gave me this house" (Interview 2). The positive attributes she described about her housing situation were living in a safe neighborhood and not being homeless. She then qualified her statement and described her concern with not owning the home and being vulnerable to losing it.
Ophelia identified some purely positive social determinants of health in her photographs and no purely negative determinants. The positive determinants included transportation, her pets and her physical environment. Ophelia described a photograph of her private vehicle (Figure 37) as the first vehicle she had owned that did not have warning lights on and that it had plenty of room for transporting her grandchildren. She stated that her vehicle related to health because:

...it gets me back and forth to the doctor. It takes me ah, um, I ain't gotta- I don’t like being stressed out catching the bus and I don’t have to wait on nobody to take me nowhere or ask somebody to take me nowhere. And hearing the answer- saying, "No" (Interview 2).
Ophelia identified her yard as a positive health determinant and associated it with nature, raking leaves, playing with her dog and staying physically healthy. She also took pictures representing her pets (e.g. Figure 38) and stated that they related her health because:

You can talk to 'em; they don’t talk back to you… They very smart… it keeps- I don’t run much, but I leave 'em at the house and they’ll chase me. You know what I’m saying? Working on my legs and stuff and keeping the weight off of him. He’ll run back and forth, all around the house. He likes to play. And I think it is- I think that with my health it’s just- it’s um, keeping me less stressed. (Interview 2)
Each of the positive social determinants acted to counter Ophelia’s descriptions of the social determinants from the model discussed in the next section.

4.8.2.3.2 Social Determinants of Health: Ophelia

Like many of the social determinants Ophelia identified in her photographs, she described motherhood as both positively and negatively impacting her health. When asked to recount the key events in her life as a mother, she told her story of becoming pregnant at the age of 15 years by a much older man. She described being "excited" about being a mother because she enjoyed playing with dolls. She ultimately revealed that as she reflected on that situation as an adult, she realized that the man had had control over her, he lived a double life with another family and that it was actually a case of child molestation (Interview 1). Ophelia reported using her life
lessons and circumstances as learning tools for her children, grandchildren and even as a peer counselor. She stated that she tells her grandchildren that "you can't trust everybody - even the ones you know" (interview 1). Ophelia also expressed concern that her teenage grandchildren were rebellious and that:

They don’t understand dealing with this disease and still I get on ‘em-sometimes I used to forget to take my medicine, you know what I’m saying? And that would be stressful out. I mean I don’t fuss no more I just um, put it in God’s hand and like I told you if they won't listen to me, the people downtown will take care of ‘em. I can’t keep putting, I mean I do everything I can you know? Daily I put ‘em before me (Interview 1).

Ophelia reported that she often feels both tired and stressed as she mothers her grandchildren. She spoke overtly positively about mothering when asked directly about its positive aspects. For example, when I asked what gave her the most pleasure about mothering she stated "...it just motivates me, keeps me going- that’s what keeps me going really. If I lived here by myself, I’d be real lonely and depressed more (Interview 1). Ophelia’s perception of motherhood was neither overtly positive or negative, but she ultimately identified that, for her, it was the most positive social determinant of health in the model. As such, Motherhood (~M) is reflected as a vector exerting force in a positive direction from the health experience plane.

Ophelia confirmed that she had experienced acts of racism and when she gave examples of such experiences she spoke about racism and class from an intersectional perspective. She described these determinants as mutually constituted vulnerabilities
and revealed a conflict she perceives between various racial communities:

But ah, and then it's like um, when we go to the food bank the other people get more food than we did, like the Mexicans. White and Blacks don't get nothin'. You know what I'm saying? It's all about the Mexicans in North Carolina. I don't see many White families in line. At the [name of church] we get little food, we get clothes for the babies, we get once in line- we can see the Mexicans with baby strollers (Interview 3).

When asked to describe how these experiences impact her health she stated it:

...stress[es] me out, sometimes forgetting to take my medicine and-I let my doctor- I be honest with my doctor and I don’t keep it from her. I let her know I messed up two or three days. I done went two months without taking meds- I was stressed out (Interview 3).

Ophelia’s descriptions of race and racism (R) on her health were all negative and therefore reflected as a vector exerting force in a negative direction from the health experience plane.

Ophelia described her financial circumstance and socioeconomic class as negatively impacting her health and the well-being of her grandchildren because she does not feel as though she can provide them with the things they need and want.

Although Ophelia had Medicaid for health insurance, she did not feel as the coverage was adequate. She stated:

I mean Medicaid don’t cover nothing really anymore. You know what I’m saying?...I do have AIDS, I have Hepatitis C. I have my leg problem, breathing problem. I got an enlarged heart. So what Medicaid gonna pay for? And in all, I pay like $277 for my medication, with the copay $3 every month (Interview 3).
Ophelia denied experiencing discrimination based on her class but attributed that largely to the fact that she does not tell people her business. She emphatically stated, “NO, I don’t tell my business... No. Like I said I’m the type of person I don’t let people know- they would never know nothing was wrong with me” (Interview 3). Nonetheless, Ophelia identified this particular social determinant as the determinant most negatively impacting her health; thus, class (C) is reflected as a vector exerting force in a negative direction from the health experience plane.

Ophelia denied that she had experienced gender discrimination, but she reported that her gender does impact her health. She stated:

Well with me, I feel that um, we can’t do things normal. When I mean normal, like ah, companionship. You just can’t um, it stresses me out and like I got a husband, you know what I’m saying, but he’s not HIV positive. But what I went through- is trying to explain to him about my disease...And then I feel that when a person is like in my predicament people take advantage of me, especially your companion (Interview 3).

While Ophelia denied gender inequality or discrimination, her description of her history of sexual assault resulted in gender (G) being reflected as a vector exerting force in a negative direction from the health experience plane.

Ophelia described experiences of HIV-related stigma and seemed to feel them most acutely from her own family. In particular, she described her mother-in-law as hurtful, insisting she drink from paper cups in her home and making her feel unwelcome. Ophelia denied, however, that her children had ever experienced stigma
because of her HIV status and she was confident that they would defend her. She stated, “No, my children they’ll fight somebody that disrespect them.” Ophelia also reported that she would not accept people disrespecting her and stated, “I’ll have none of that” (Interview 3). Because HIV-related stigma (S) by definition is not positive in nature and Ophelia stated that she had experienced it, it was reflected as a vector exerting force in a negative direction from the health experience plane.

Ophelia viewed many of her life circumstances as quite negative. During the interviews, she appeared to be working very hard to describe them from a positive perspective, sometimes calling on her spiritual beliefs to aid her in this effort.

| 4.8.2.3.3 Self-assessment of Health: Ophelia |

> When asked to define health in her own words, Ophelia stated, “I mean I can deal with- I mean I’d rather have- I mean I don’t rather have it but if I had a choice I’d rather have this than cancer” (Interview 3). Ophelia’s answer seemed to suggest that health was about being less ill than others and when asked if she considered herself healthy based on her own definition, she responded:

> No, I can’t do the normal things I want to do like have sex-relation or kiss ‘cause I’m scared that I might have an infection in my mouth, you know what I’m saying-you know what I’m saying? So I’m not normal and it stresses me out that I’m not normal. And it stresses me out that I see people do normal things and I can’t do it. It just stresses me out (Interview 3).

Per her assessment, the health self-assessment vector (-) in Ophelia’s vector model is
reflected as exerting force in a negative direction from the health experience plane.

![Vector Model: Ophelia](image)

**Figure 39: Vector Model – Ophelia**

### 4.8.3 Phase Three: Frame Analysis

In Erving Goffman’s (1974) original work on frame analysis he defined frames as “schemata of interpretation.” (p. 21). The goal of this particular analysis was to develop a deeper understanding of the potential variable and contesting schemata of interpretations, or frames, African American mothers living with HIV and in poverty have regarding their social location as it pertains to health (Goffman, 1974). Analysis of the fourteen cases revealed a variation in the configuration of the social determinants as mutually constituted vulnerabilities, mutually constituted strengths and opposing determinants. Here, I used qualitative comparative analysis (i.e. cross-case analysis) of
the individual case vectors to help explain their relationships and hypothesize about the way participants frame their social location based on combinations of the determinants and their self-assessment of health. Henceforth, the qualitative comparative findings will be called the frame analysis.

I propose three potential participant frames of social location – emancipatory, situational and internalized - that are based on the biographies of the participants and the individual vector analyses developed for each. An important part of distinguishing the frames is identifying the key moral or normative concern driving each contesting frame (Britt & Evans, 2007; Haley & Sidanius, 2006). For example, the primary normative concerns for mothers with a situational frame is maintaining positive maternal identity and maternal–child relations (Sandelowski & Barroso, 2003). In a meta-synthesis of 56 qualitative reports examining motherhood in the context of HIV infection, the researchers found that protecting one’s children and preserving a positive maternal identity were the two primary goals of the mothers as they dealt with the illness and its associated social consequences. One of the great paradoxes of motherhood in the context of HIV, however, is that while motherhood is generally considered a cultural norm for women, it is alternately viewed as a deviant act for women living with HIV (Sandelowski & Barroso, 2003). So, my hypothesis in developing these frames is that as woman becomes less committed to the notion of
motherhood in HIV as a normative act and responds more acutely to social stigma and the need to justify any acts of “deviance,” space opens up for the development of frames that respond to those social circumstances. It is important to note that for African American mothers living with HIV and in poverty, raced and classed discourses are likely to serve to intensify the stigmatizing effects in their contextual environment (Bottero, 2004; Mullings & Schulz, 2006).

Table 7 gives an overview of the three prosed frames location – emancipatory, situational and internalized – and details how they compare to one another.

<table>
<thead>
<tr>
<th></th>
<th>Emancipatory</th>
<th>Situational</th>
<th>Internalized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motherhood buffers the negative effects of HIV infection</td>
<td>N/A</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>HIV infection enhances maternal identity and/or maternal-child relations</td>
<td>N/A</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Social determinants have deleterious impact on health</td>
<td>Low</td>
<td>Variable</td>
<td>High</td>
</tr>
<tr>
<td>Propensity for cognitive reframing</td>
<td>High</td>
<td>Low</td>
<td>N/A</td>
</tr>
<tr>
<td>Health Self-Assessments</td>
<td>Positive</td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Source of Moral Authority (moral or normative concern)</td>
<td>Transcending oppressive discourses</td>
<td>Maintaining positive maternal identity and maternal-child relations</td>
<td>Normality in one’s social context [which notably values the dominant culture of white, middle class mothers not living with HIV]</td>
</tr>
</tbody>
</table>
Table 8 provides exemplar quotes for how the frames were dichotomized into high and low for each frame and are drawn from a the larger data set of exemplar quotes for each individual participants case descriptions are found in Appendix J-W.
<table>
<thead>
<tr>
<th>Emancipatory Frame</th>
<th>Situational Frame</th>
<th>Internalized Frame</th>
<th>Health Self-Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High</strong>...there's nothing that's keeping me from taking care of myself, I just feel like it's not...I mean I'm doing, well first of all I give honor to the man above. And other than him I just feel like I'm doing you know everything possible. (Participant 005, Interview 3)</td>
<td>...I think it [HIV] made me be a better mom...Because I just wanted like the relationship to be...like a strong bond you know. Like I said in the beginning I didn't think I was going to live as long as I have. So I wanted every moment to count. And so our relationship, we're very close, very close...and I think that has something to do with it. Not saying that if I didn't have it you know I wouldn't be close with my kids but I think it has impacted my life a little more you know? (Participant 005, Interview 1)</td>
<td>[Tells story of feeling discriminated against at Food Bank for her race] I: Mm, how about caring for your HIV, does that experiences impact caring for your- ? P: Yeah, it does stress me out, sometimes forgetting to take my medicine and I let my doctor- I be honest with my doctor and I don't keep it from her. I let her know I messed up two or three days. I done went two months without taking meds- I was stressed out. (Participant 012, Interview 3)</td>
<td>P: Me. The end. [Laughter] I: So based on your definition do you consider yourself healthy? P: Yes ma'am. (Participant 011, Interview 3)</td>
</tr>
<tr>
<td><strong>Low</strong>They don't understand dealing with this disease and still I get on 'em- sometimes I used to forget to take my medicine, you know what I'm saying? And that would be stressful out. I mean I don't fuss no more I just um, put it in God's hand and like I told you if they won't listen to me, the people downtown will take care of 'em. I can't keep putting, I mean I do everything I can you know? Daily I put 'em before me. (Participant 12, Interview 1)</td>
<td>Taking care of kids, having kids, having children running around and working....Cause I know for me, for years I like I got to work, I got to work and put my doctor's appointments to the sides because I had to go. And I rescheduled, I rescheduled. And then it becomes a, after you're done reschedules it's like yeah forget about it-I'm feeling fine, I never even think about, 'no I need to go get checked out.' (Participant 001, Interview 3)</td>
<td>Um, I guess the HIV stigma but I'm gonna do me regardless. (P laughs) I have a- a drive and a purpose and none of those can- that's on that list can affect me. So- (Participant 018, Interview 3)</td>
<td>I mean I can deal with- I mean I'd rather have- I mean I don't rather have it but if I had a choice I'd rather have this than cancer.... I'm like, 'God, why they got to suffer too?' They just - cancer is like AIDS you know what I'm saying? I: Um, so based on your definition of health or being healthy um, do you consider yourself healthy? P: No, I can't do the normal things I want to do like have sex-relation or kiss 'cause I'm scared that I might have an infection in my mouth, you know what I'm saying-you know what I'm saying? So I'm not normal and it stresses me out that I'm not normal. And it stresses me out that I see people do normal things and I can't do it. It just stresses me out (Participant 012, Interview 3)</td>
</tr>
</tbody>
</table>
Finally, the qualitative comparative analysis (QCA) table shows how the dichotomous variables were used to develop these frames (Table 9).

**Table 9: Qualitative Comparative Analysis Table**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Race</th>
<th>Class</th>
<th>Gender</th>
<th>HIV-related Stigma</th>
<th>Motherhood</th>
<th>Health Self-Assessment</th>
<th>Social Location Frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>M</td>
<td>+</td>
<td>Internalized</td>
</tr>
<tr>
<td>002</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
</tr>
<tr>
<td>003</td>
<td>R</td>
<td>C</td>
<td>–G</td>
<td>S</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
</tr>
<tr>
<td>004</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
</tr>
<tr>
<td>005</td>
<td>–R</td>
<td>C</td>
<td>–G</td>
<td>nd</td>
<td>–M</td>
<td>+</td>
<td>Emancipatory</td>
</tr>
<tr>
<td>006</td>
<td>nd</td>
<td>C</td>
<td>–G</td>
<td>nd</td>
<td>–M</td>
<td>+</td>
<td>Emancipatory</td>
</tr>
<tr>
<td>008</td>
<td>nd</td>
<td>nd</td>
<td>–G</td>
<td>nd</td>
<td>–M</td>
<td>+</td>
<td>Emancipatory</td>
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<tr>
<td>009</td>
<td>R</td>
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<td>S</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
</tr>
<tr>
<td>011</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
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<tr>
<td>012</td>
<td>R</td>
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<td>S</td>
<td>–M</td>
<td>–</td>
<td>Internalized</td>
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<tr>
<td>013</td>
<td>nd</td>
<td>C</td>
<td>G</td>
<td>S</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
</tr>
<tr>
<td>016</td>
<td>R</td>
<td>C</td>
<td>G</td>
<td>nd</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
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<td>017</td>
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<td>–C</td>
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<tr>
<td>018</td>
<td>nd</td>
<td>nd</td>
<td>nd</td>
<td>nd</td>
<td>–M</td>
<td>+</td>
<td>Situational</td>
</tr>
</tbody>
</table>

nd = non-determinant

In the following sections, I outline the three proposed contesting frames and their effect on self-assessment of one’s health. The individual participant case analyses, vector models and frame analyses for all fourteen cases can be found in Appendices J-W.

**4.8.3.1 Emancipatory Frame**

All of the participants in this sample self-identified as African American, female mothers living with HIV; and, therefore they all at least minimally accepted their
diagnosis with HIV infection and its associated health risks, their decision to nurture and care for their child(ren) and their socially constructed identity as women and African American/Black. [I did not ask them to specifically self-identify with a particular class, rather eligibility was determined based on income level or qualification for specific health/social services.] Nonetheless, not all of the women appeared to identify equally with their health condition or socially constructed identities and the distributions are noted in the contesting frames.

Two aspects of what participants said with respect to motherhood and HIV and the intensity with which they perceived the deleterious impact of the social determinants of race, class, gender and HIV-related stigma on their health were helpful in discriminating between a high and low emancipatory frame. The first was the extent to which they described the relationship between their HIV infection and motherhood. None of these participants in this frame, participant 005, 006 and 008, had disclosed their HIV status to their children and while they described their maternal-child relations and identities as mothers in positive ways, they deflected the questions suggesting motherhood might impact their HIV infection (positively or negatively) or having HIV might impact their mothering role or the maternal-child relations (positively or negatively). For example, one participant who is a step-mother and also pregnant with her first biological child, stated, “And motherhood it doesn’t affect [my
HIV]...I don’t think it will affect it. I mean not at all” (Participant 008, Interview 1). A second feature was the extent to which they minimized the deleterious effects of the social determinants of race, class, gender and HIV-related stigma on their health during the interviews. The participants either reported that they had no impact on their health and they were coded as non-determinants or they reported that they had a positive impact on their health. The participants appeared to be attempting to transcend the negative social connotations associated with their disease and socially constructed identities by making an intentional discursive move away from a narrative of oppression to emancipation (Sandelowski & Barroso, 2003). These discursive countermoves were evident by their high propensity for cognitive reframing within the interviews (Robson & Troutman-Jordan, 2014). In a concept analysis of the cognitive reframing, Robson and Troutman-Jordan (2014) provided an operational definition of the concept saying that it can either be a therapeutic technique in cognitive-behavioral therapy, or when one self-alters “perceptions of a negative, distorted or self-defeating belief with the goal of changing behaviors and/or improving well-being” (p.58). Two participants identified their religious/spiritual beliefs as the tool for positively reframing their situations (Grossoehme et al., 2012), but the other did not. The participants that tended to reframe their circumstances also tended to give positive self-assessments of their own health based on their personal definition of health. Table 10
provides the frequency each participant reframed their social and health circumstance throughout the three interviews.

### Table 10: Propensity for Cognitive Reframing

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>001</th>
<th>002</th>
<th>003</th>
<th>004</th>
<th>005</th>
<th>006</th>
<th>008</th>
<th>009</th>
<th>011</th>
<th>012</th>
<th>013</th>
<th>016</th>
<th>017</th>
<th>018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reframing Frequency</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>7</td>
<td>10</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

#### 4.8.3.2 Situational Frame

The assessment of the situational frame intensity was multifaceted and rested heavily on the moral or normative concern driving this frame: maintaining positive maternal identity and maternal–child relations. The participants in this frame [participants 002, 003, 004, 009, 011, 013, 016, 017, and 018] were strongly committed to a notion that motherhood buffered the negative effects of their HIV infection and that having HIV enhanced their maternal identity and relationships with their children. They often described motherhood as the impetus for taking care of their health and living as long and as well as possible. They also positively described their role as mothers and their relationships with their children. Like the participants with emancipatory frames they utilized cognitive reframing, but they did so to a lesser degree and in the context of motherhood. In other words, maintaining a positive maternal identity and maternal-children relations was the impetus for the reframing. A second aspect of the descriptions provided by this group of participants was that they had highly variable perceptions of the impact the specific social determinants (i.e., race,
class, gender and HIV-related stigma) had on their health. As a result, there is very little symmetry in the vectors representing these determinants in the individual vector models of the participants with this frame for their social location; rather, the configuration of the determinants is highly variable based on their personal biography. For example, a participant might have positively reframed her perceptions of racism but then clearly articulated the negative role that her financial/material resources and class inequality had on her health making no attempt to positively construe its detrimental impact. Because these participants adhered so strongly to their desire to maintain their positive maternal identity and maternal-child relations, they also reported positive health self-assessments attributing much of their health to these two aspects of their lives.

4.8.3.3 Internalized Frame

Two participants in the sample were noted to have internalized frames for their social location, participants 001 and 012. Two aspects of what participants said with respect to motherhood and HIV and the intensity with which they perceived the deleterious impact of the social determinants of race, class, gender and HIV-related stigma on their health were helpful in discriminating between a high and low internalized frame. The first was the extent to which they negatively described the relationship between their HIV infection and motherhood. These participants often
detailed the negative impact motherhood had on their ability to care for their own health and needs. They would describe the fatigue they incurred from mothering and difficulty they had in maintaining their health as they cared for the children. Additionally, they reported either negative interaction with their children and/or did not disclose instances of how HIV enhanced their relationships with their children. The second feature was the extent to which they emphasized the deleterious effects of the social determinants of race, class, gender and HIV-related stigma on their health during the interviews. Participants reported instances of racism, gender inequality (e.g., sexual assault), HIV-related stigma and difficulties managing their health conditions with current financial/material resources. These participants rarely reframed their situations and gave negative or equivocal self-assessments of their own health based on their personal definition of health.

The important question of these analyses therefore is what are the health implications of these contesting frames of social location and do some of the observed frames potentially lead to greater health challenges and vulnerability to poorer health outcomes (Shi & Stevens, 2010). Further, are there potential health interventions specific to mothers with varying frames, both at the process and structural levels, that can help women generate more positive health self-assessments. These central questions will be addressed in the discussion section of this chapter.
4.9 Discussion

The social location and health experiences of African American mothers living with HIV operates at the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood (Caiola et al., 2014). Using an intersectional approach, I analyzed data derived from in-depth interviewing and visual methods and sought to explain how the intersection of social determinants influenced health experiences of African American mothers living with HIV in the southeastern region of the United States. Broadly, I found that the proposed conceptual framework was insufficient to capture the complex social location of experiential aspects of daily life with HIV and motherhood for African American women. While I found similarities in the structural influences constraining the narratives of the mothers, there was equally as much fluidity and heterogeneity in their descriptions of social determinants of health over time. In accordance with an intersectional approach, I found that these intersecting determinants greatly influenced health experiences in both positive and negative ways and propose that participants developed frames, or ways for interpreting, their social locations, which may have significant health implications. These findings support the literature on individual social determinants of health for African American mothers living with HIV and build on how these individual social determinants intersect to impact their health experiences. I have organized the findings into the following broad
categories: beyond the model, a case for strength-based approaches, familiar intersections, and heterogeneity and fluidity. As I discuss each of these categories of findings I highlight those facets that are potentially amenable to intervention and can be meaningfully addressed at both structural and process levels (Fleury & Sidani, 2012; Sidani & Braden, 2011).

4.9.1 Beyond the Model

Using an intersectional approach and the participatory methods described, six additional social determinants of health, not included in the intersectional model developed for the study, were identified by the participants. Each of these adds to the literature on the configuration of intersecting social determinants of health relevant to African American mothers living with HIV, expands the proposed conceptual model, and identifies aspects of the problem that may be meaningfully addressed through structural interventions.

4.9.1.1 Social Support

In the era of highly active antiretroviral therapy (HAART), HIV has shifted from being an acute, fatal disease to a chronic illness in this country. Concomitantly, the importance of social support for people living with HIV has become increasingly recognized as a critical factor as they live longer and healthier lives (Mignone et al., 2014). Higher levels of perceived social support has been associated with longer HIV
survival rates for parents living with HIV (Lee & Rotheram-Borus, 2001), and being part of diverse social network has also been associated with longevity for those living with chronic illnesses (S. Cohen & Janicki-Deverts, 2009). Moreover, the findings from a qualitative study of African American mothers living with HIV found that the mothers viewed their children as a significant source of social support facilitating their medication adherence and positive health-seeking behaviors (Edwards, 2006), suggesting an interesting intersection between motherhood and social support. The finding of social support as a significant positive social determinant of health for participants in this study supports this literature. Whether the support people in the lives of participants offered encouragement to perform health-seeking behaviors, gave emotional support or acted as role models, the participants perceived them as positively impacting their health and helping them to cope with their HIV diagnosis. Much of the work examining social support and health outcomes, however, is correlational not causal and there a number of mechanisms that may be influencing these associations (S. Cohen & Janicki-Deverts, 2009). Nonetheless, the findings from this study offer additional empirical evidence supporting the need to further examine the association and offer an opportunity to consider how social support may specifically function as a positive social determinant of health for African American mothers living the HIV as well as the structural approaches needed to generate more
healthful social environments (S. Cohen & Janicki-Deverts, 2009).

4.9.1.2 Religiosity

Consistent with previous research on the centrality of organizational and non-organizational religiosity in the lives of African Americans, Chatters and colleagues (2009) found that they report higher levels of religious participation than other ethnic groups in the United States (Chatters, Taylor, McKeever Bullard, & Jackson, 2009). Additionally, community-based partnerships can potentiate traditional medical setting HIV interventions: the strategic plan of the CDCP Heightened National Response to Address the HIV/AIDS Crisis among African Americans urged faith-based organizations and faith leaders to collaborate with health partners to scale up the HIV intervention strategies for African Americans (CDCP, 2007a). While not enacted and fixed at the committee level, the National Black Clergy for the Elimination of HIV/AIDS Act was introduced to Congress in both 2009 and 2011 to support Black Churches (churches serving primarily African Americans) with resources for HIV intervention initiatives ("National Black Clergy for the Elimination of HIV/AIDS Act of 2011,” 2011). Several studies, however, demonstrate the potential effectiveness of faith-based and public health partnerships in HIV intervention initiatives (Agate et al., 2005; Berkely-Patton et al., 2010; Griffith, Campbell, Ober Allen, Robinson, & Kretman Stewart, 2010; Wingood, Simpson-Robinson, Braxton, & Raiford, 2011). The findings from this study
also support the centrality of religion in the lives of African American mothers living with HIV and the critical need for faith-based, public health partnerships. The participants identified their religious beliefs and association with the Black Church as influential in their lives and the lives of their children, acting as positive social determinants of health by offering guidance, additional social support and opportunities for service to others. Black Churches have a history of mobilizing social change within their communities (Berkely-Patton et al., 2010) and faith-based, public health partnerships offer potential as an important structural approach for change in the racial disparities noted in the HIV/AIDS epidemic requiring further investment in support tools, capacity building for faith leaders and community-based intervention research (Berkely-Patton et al., 2010; De Marco et al., 2011).

4.9.1.3 Animal Companions

To my knowledge, there are three studies exploring the potential health effects of animal companionship for persons living with HIV and each point to the positive influences animal companions have on emotional and physical wellbeing. Swart Kruger and colleagues (2014) found that dog ownership increased perceived wellbeing in military veterans living with HIV/AIDS by acting as a stress reliever and increasing opportunities for physical activity, companionship, and responsibility (Swart Kruger, Stern, Anstead, & Finley, 2014). When examining the caregiving and social networks of
persons living with HIV, Mignone and colleagues (2015) found that nearly half of their participants were living with pets and identified their pets as sources of strength, resiliency and social support. Although older, the findings from the large 1991 Multicenter AIDS Cohort study showed the positive mental health benefits of pet ownership for those persons diagnosed with AIDS as they reported less depression, particularly when they also reported fewer social support persons (Siegal, Angulo, Detels, Wesch, & Mullen, 1999). The finding of animal companions as a significant positive social determinant of health for participants in this study supports this literature. Whether the animal companions offered companionship, helped to provide joy, decreased stress levels or offered opportunities for physical exercise, the participants perceived them as positively impacting their health and helping them to cope with their HIV diagnosis. This empirical evidence points to the need for further exploration of the influence of pet ownership in the health and well-being of person living with HIV as well as possible animal-assisted intervention strategies. In a recent literature review assessing the empirical evidence for the broader health benefits of animal companionship on cardiovascular health, quality of life and longevity, the researchers advocate for animal-assisted therapy in clinical setting and describe the current process-level efforts at the Mayo Clinic in Rochester, NY to implement animal-assistance in the therapeutic environment based on the consistent volume of data
substantiating the positive health benefits (Creagan, Bauer, Thomley, & Borg, 2015).

4.9.1.4 Physical Environment

In a comprehensive literature review exploring the health benefits associated with human contact with nature, park environments were found to hold promise for enhancing human health and well-being for urban dwelling residents, and the authors advocated structural interventions focused on public parks and natural areas as a broad “upstream” population health promotion strategy (Maller, Townsend, Pryor, Brown, & St. Leger, 2005). Greater physical activity, obesity prevention, stress reduction, coping and enhanced recovery from illness and injury are among the many health benefits associated with human contact with nature in public spaces and the built environment (D. A. Cohen et al., 2007; Coombes, Jones, & Hillsdon, 2010; Maller et al., 2005; Saelens & Handy, 2008). As a result, national health organizations such as the Institute of Medicine, the U.S. Department of Health and Human Services and the Centers for Disease Control and Prevention are calling for greater investment and government planning for these public spaces (CDCP, 2011; Institute of Medicine and National Research Council, 2009; National Prevention Council, 2011). When examining the caregiving and social networks of persons living with HIV, Mignone and colleagues (2015) found that persons living with HIV identified contact with nature and caring for plants and animals offered alternatives to the
hardships in their lives and were described as sources of support, strength and resilience. The findings from this study also support the significance of a connection with one’s physical environment and nature in promoting health for African American mothers living with HIV. Whether interaction with their physical environment offered opportunities for relaxation, reflection, exercise or recreating, the participants perceived these opportunities as positively impacting their health and helping them to cope with their HIV diagnosis. However, disparities have been noted across racial/ethnic and socioeconomic status when park availability is considered along with factors such as cleanliness and physical condition (Bruton & Floyd, 2014). Findings such as ours may help inform policy, design and maintenance of parks located in more communities such as those where African American mothers living with HIV and in poverty are more likely to reside (Bruton & Floyd, 2014).

4.9.1.5 Transportation

In a recent qualitative meta-synthesis examining the social determinants of health for African Americans living with HIV in the rural southeast region of the United States, transportation issues such as maintenance of and fuel for personal vehicles and the affordability and accessibility of public transport was a significant finding (Abbott & Williams, 2015). A systematic review of the literature examining transportation barriers and access to healthcare found that without exception poorer
individuals experienced greater transportation barriers to healthcare access leading to gaps in chronic illness management (Syed, Berber, & Sharp, 2013). The means of transportation utilized by participants in this study varied (private vehicles v. public transport such as buses and medical transport van services) and participants identified both positive and negative aspects of the various forms of transportation and associated health implications. These findings support the previous literature and the reliability, accessibility and affordability of transportation was noted as an important social determinant of health for African American mothers living with HIV. The findings of this study also add to the impressive body of research prompting the American Public Health Association (APHA) to craft Public Health and Transportation Equity principles meant to guide the transportation policies and structural interventions that prioritize health and equity in American communities (American Public Health Association, 2015). These principles advocate for policies, interventions, and research aimed at funding community-based transportation programs that expand options for vulnerable populations, conducting health impact assessments to guide policy, involving community members in transportation planning and development and establishing performance measures (American Public Health Association, 2015).

4.9.1.6 Housing

Results from the pioneering 2005 National Housing and HIV/AIDS Research
Summit involving core research and policy experts indicate that stable housing is foundational to both HIV prevention and treatment (The National AIDS Housing Coalition, 2005). Specifically, for women living with HIV in the southern region of the United States, stable housing is correlated with emotional wellbeing, positive physical health indicators, risk reduction behaviors and medication adherence (Delavega & Lennon-Dearing, 2015). The findings from this study complement the empirical evidence pointing to the importance of housing as a social determinant of health.

Fortunately, a growing body of evidence suggests that structural interventions such as “Housing First” strategies are effective with persons living with HIV and can impact physical health by increasing survival and promoting intact immunity (Buchanan, Kee, Sadowski, & Garcia, 2009). The National AIDS Housing Coalition offers further guidance for policy, research and intervention strategies aimed at broadening the concept of housing as healthcare for all persons, but specifically for persons living with HIV (The National AIDS Housing Coalition, 2005). Other examples include advocacy for the provision of affordable housing and micro-financing programs to decrease economic dependency for HIV-infected women living in poverty (Adimora & Auerbach, 2010).

The social determinants of health identified by the participants in this study individually offer opportunities to either capitalize on the strengths of African
American mothers living with HIV for the enhancement of their health or intervene where specific vulnerabilities are clearly at work. They provide direction for building on the conceptual model specified in this study as the role of the additional determinants expand its scope. For instance, good social support may certainly be an opposing determinant to HIV-related stigma experienced by a mother, while also being an implicit aspect of motherhood. Clearly, too, some of the social determinants identified by the participants are also functioning as indicators of broader social determinants already in the model; for example, housing and transportation stability function as key indicators of income inequality or poverty in this population. Nonetheless, these finding demonstrate that when the experiential aspects of daily life with HIV are considered, a broader and more complete conceptual approach is likely to emerge.

4.9.2 A Case for Strength-based Approaches

Overall, the participants primarily chose to identify positive social determinants of health, or what they deemed to be strengths, as they cared for themselves and their HIV. This important finding supports those in other studies in which participants’ tendency to focus on positive aspects of their lives in research using photography has been noted. One possible explanation is that the prevailing social convention of photography is to depict what Guillemin and Drew (2010) describe as “happy snaps,”
portraying ideal representations of our social lives (p. 180). Other researchers have suggested that it may be due to the sensitivity of negatively portraying of one’s life, the difficulty in capturing visual images reflecting negative emotions and that taking such pictures is just not an enjoyable process (Zartler & Richter, 2014).

In the context of this study, it is particularly important to acknowledge any potential power differentials in the research process that may have influenced participants to represent their lives in primarily positive light. While participatory visual methods have the potential to democratize the research process by asking the participants to co-create knowledge, the methods in and of themselves do not reduce existing power imbalances of a dominant culture (Packard, 2008). Despite intentional steps I took in the study design to limit such power differentials, it is important that I acknowledge the longstanding sociocultural context in which this study took place, the fact that I am a white researcher working with African American women, and that I asked the participants to openly report their vulnerabilities in a research setting that has historically been wrought with unbalanced power differentials such as racism. Thus, asking people to expose themselves and their vulnerabilities in such a context is a challenge and might be a possible explanation for the participant’s emphasis on positive social determinants of health. The power exerted by the research community, myself included, in categorizing specific populations as vulnerable is also important to
consider. Too often, we approach health research from a deficit perspective rather than examining health-promoting (positive) social determinants of health (Thygeson, 2013). A mother whose health experience is primarily one of strength and resilience, rather than vulnerability, would likely choose to represent that lived experience. As such, this particular finding offers a case for more strengths-based approaches to health research and practice. It is incumbent upon health researchers to acknowledge these strengths and make every attempt to create social environments that enhance these capacities. Recent guidelines based on a review of interventions for enhancing linkage and retention in HIV care released by the International Association of Physicians in AIDS Care (IAPAC) support this finding and they recommend strength-based case management framed with a strength-based theory of cognitive therapy, a process level intervention, for all newly diagnosed patients (Okeke, Ostermann, & Theielman, 2014).

4.9.3 Familiar Intersections Functioning as Systems of Oppression

The findings from the phase one content analysis bring to light the familiar interlocking systems of oppression of race, class, and gender conceptualized and documented in contemporary intersectional scholarship (McCall, 2009). Additionally, because of the contextual nature of this study and its focus on health determinants of a specific disease (HIV) in a specific population (mothers), the findings also illuminate how disease-specific phenomena such as HIV-related stigma and socially constructed
roles such as motherhood may also interact simultaneously as mutually constituted strengths, mutually constituted vulnerabilities and opposing determinants of health. The idea of mutually constituted strengths and opposing determinants such as motherhood conceptually broadens the intersectional model for African American mothers living with HIV initially proposed for this study. Rather than “mutually constituted vulnerability” at the center of the model, I would now suggest that the concept of “social location” more accurately captures how mothers socially locate themselves and navigate those relationships steeped in power differentials (McCall, 2009).

It is not surprising that core findings reflect the mutually constituted vulnerabilities stemming from systems of oppression based primarily on race, gender, class and HIV-related stigma in predictable ways. These findings support the structural inequalities at work in producing poorer health outcomes for this population and speak to the increasing recognition that structural interventions, altering the social context in which people make health choices, possess the greatest potential for impact on population health (Frieden, 2010). These findings support three potential structural interventions targeting the race-, class-, gender –inequality, HIV-related stigma and motherhood intersection described in this study. One, the evidence from this study supports the need for a change to the North Carolina Senate’s draft budget which
proposes a $6 million dollar recurring cut the North Carolina AIDS Drug Assistance Program (ADAP) which could conceivably put hundreds of people, including HIV-infected mothers living in poverty, back on the waiting list for financial assistance to pay for their medications (North Carolina AIDS Action Coalition, 2015). Two, evidence from this study could be used to advocate for the end to HIV criminalization laws that are found in the North Carolina health code and serve to perpetuate the HIV-related stigma negatively impacting the health and wellbeing of participants in this study (Association of Nurses in AIDS Care, 2014; National HIV/AIDS Strategy for the United States, 2010; The Center for HIV Law & Policy, 2014). Three, evidence from this study supports the need to advocate for the full scope and impact of the Affordable Care Act via Medicaid expansion into North Carolina and many other southern states, which has been shown to decrease delays in care and mortality particularly among the poor, nonwhite communities most impacted by HIV (Adimora, Ramirez, Schoenback, & Cohen, 2014; Sommers, Baicker, & Epstein, 2012).

4.9.4 Heterogeneity and Fluidity

While the findings highlighted through the content analysis bring to light the interlocking systems of oppression of race, class, gender and HIV-related stigma conceptualized in the intersectional model, the findings from the storyline graphs, vector model analysis and frame analysis all point more specifically to the lived
experience of individual mothers responding to those systems of oppression, the social construction of their specific social locations and how they then interpret and navigate the social relationships and power differentials inherent in those locations (McCall, 2009). These findings, in particular, illuminate the heterogeneity and fluidity in social locations as framed from the mother’s perspectives through time, context, and space (Caiola, McGee, & Harmon, 2015, in press; Weber, 2006). Following, I review each of the proposed frames of social location – emancipatory, situational, and internalized – and suggest their potential health implications and interventions.

4.9.4.1 Emancipatory Frame

The participants with high emancipatory frames appeared to be attempting to transcend the negative social connotations associated with their disease and socially constructed identities by making an intentional discursive move away from a narrative of oppression to that of emancipation (Sandelowski & Barroso, 2003). They did so by making no association between being mothers, generally considered a cultural norm for women, and their HIV disease, which it is alternately viewed as deviant (Sandelowski & Barroso, 2003). Additionally, they minimized the deleterious effects of the social determinants of race, class, gender and HIV-related stigma on their health. These participants attempts to transcend or emancipate themselves from the negative social characterizations associated with their race, class, gender and HIV status might be
likened to the Superwoman Schema or the Sojourner Syndrome suggested in the health literature focused on health disparities in African American women (Mullings, 2005; Woods-Giscombe, 2010). While slightly different in their conceptualizations, each of these schema is described as an interpretive frame of resistance and resilience developed by African American women in response to the intersecting and historical oppressions of race, class and gender from slavery forward (Mullings, 2005; Woods-Giscombe, 2010). These interpretative frames are also described as survival strategies having both negative and positive health consequences (Mullings, 2005; Woods-Giscombe, 2010). Benefits of this frame may include resiliency, preservation of self-identity, family and community (Woods-Giscombe, 2010). Indeed the participants in this study with high emancipatory frames frequently cognitively reframed their circumstances, exuded a sense of resiliency, and provided positive self-assessments of health. Detriments of the frame may include strain in interpersonal relationships, stress and embodiment of stress that may lead to the stress-induced health disparities noted in this population by the literature on “weathering” and allostatic load (Geronimus et al., 2006). Another potential health implication of such a frame is “not claiming” among African American women with chronic illness (McKenzie & Skelly, 2010). “Not claiming” is based on faith beliefs that allow one to hand both the healing and the disease itself over to God (McKenzie & Skelly, 2010). Two of the participants with high
emancipatory frames described such beliefs and made the following statements regarding their HIV infection: “… heard it plenty of places that if you don’t claim it, you ain’t got it.” (Participant 006, Interview 1) and “But thanks be to God I don’t have to claim it. I can rebuke it in the name of the Lord.” (Participant 005, Interview 1). This level of emancipation from one’s health circumstances generates concern that these women may neglect self-care practices and health maintenance (McKenzie & Skelly, 2010). Process level interventions for mothers with high emancipatory frames would then need to be directed toward stress and coping management as well as ongoing assessment of and assistance with HIV self-management strategies congruent with her faith beliefs.

4.9.4.2 Situational Frame

The participants with high situational frames were strongly committed to a notion that motherhood buffered the negative effects of their HIV infection, that having HIV enhanced their maternal identity and relationships with their children, and had highly variable perceptions and reframing of the impact the specific social determinants (i.e., race, class, gender and HIV-related stigma) had on their health. Depending on their propensity for reframing and transcending the negative social characterizations associated with their race, class, gender and HIV status, these women may too be vulnerable to health benefits and liabilities of Superwoman Schema or the Sojourner...
Syndrome suggested previously (Mullings, 2005; Woods-Giscombe, 2010). More likely, however, health implications are likely to stem from the moral or normative concern driving this frame – motherhood. These women may be particularly vulnerable to any threats to a positive maternal identity or maternal-child relations. Examples include the loss of a child, a child acquiring HIV perinatally, or stigma experienced by the child secondary to the mother’s HIV status. Additionally, all process level interventions for mothers with high situational frames will need to acknowledge the centrality of motherhood (Sandelowski & Barroso, 2003) and be attentive to the family and caregiving responsibilities she is likely to prioritize (Harrison, Short, & Tuoane-Nkasi, 2005).

4.9.4.3 Internalized Frame

The participants with high internalized frames distinguished themselves by the extent to which they embodied or internalize the negative aspects of mothering as it related to their HIV infection, and emphasized the deleterious effects of race, class, gender and HIV-related stigma on their health. The potential health ramifications of this particular frame are abundant, align with the literature exploring the health implications of all stigmatizing conditions and may include such things as aggravated symptoms, depression, impaired coping, decreased utilization and access to health services, poor physical health, lack of social support, weathering and high allostatic
load measures (Geronimus et al., 2006; Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Logie & Gadalla, 2009; Sandelowski & Barroso, 2003). Process level interventions for mothers with highly internalized frames will clearly need to focus on aspects of mental and emotional health and stigma reduction interventions (Barroso et al., 2014; Stangl, Lloyd, Brady, Holland, & Baral, 2013).

The discussion of frames and potential process level interventions is potentially problematic as it has a tendency to emphasize individual risk and behavior and focus on helping people to cope with oppressive social conditions; thus, distracting attention from the numerous and difficult structural changes and interventions that need to occur in order to address the systems of oppression perpetuating the disparate health outcomes of African American mothers living with HIV (Mullings, 2005; Woods-Giscombe, 2010). Nonetheless, I argue that the vector and frame analyses findings are important because they provide empirical evidence supporting the presence of heterogeneity among a demographically similar group of people, challenge the assumption that disparate health outcomes are intractable in such communities, and work against the persistent marginalization of communities based on demographic characteristics (Bauer, 2014). Additionally, a greater understanding of a patient’s health experiences, social location, and the social forces influencing their healthcare decisions is critical for providers as they work with patients to develop realistic and attainable
healthcare plans and goals (Safford et al., 2007).

4.9.5 Limitations

The findings from this study may be limited by selection bias in the recruitment participants, study attrition, and the research protocol differences in the study phases. All participants were all recruited because of their prior involvement in HIV research and/or their treatment at an infectious diseases clinic. Those previously involved in research were part of a study examining the efficacy of a stigma reduction intervention and they had to meet a minimum threshold on an internalized stigma scale for enrollment in that study. As such, these women may have higher levels of internalized stigma than the general population of persons living with HIV. The participants recruited from the infectious disease clinics received information about the study from their provider or a flyer in the clinic, and thus were at least minimally engaged in care and may have experiences different from those that are not actively engaged in HIV care.

Study attrition, meaning those mothers not completing all three interviews, was high at 21% with 4 out of the 19 participants enrolled not completing all three interviews. In addition, one participant who completed all three interviews was not included in the analysis because a change was noted in her eligibility status during her final interview. Reasons for study drop-out included homelessness, emotional distress,
hospitalization, and one unknown.

The study was intentionally completed in phases so that the visual methods protocol could be sufficiently piloted. The consent process regarding photograph inclusion, therefore, was slightly altered for participants 006-019 and storyline graphs were added to the research protocol in order to help illuminate the temporal aspects of the problem noted with first five participants. As a result, I was only able to construct storyline graphs on 11 of the 19 participants and no pictures of identifiable people were allowed.

4.9.6 Implications for Clinical Practice

The exploratory findings from this study have implications for clinical practice. To my knowledge, no studies have described the intersection of race-, class-, gender-inequality, HIV-related stigma and motherhood; moreover, few studies have described intervention approaches targeted specifically to mothers living with HIV, with the goal of keeping them healthy (Davies et al., 2009; Futterman et al., 2010; Glover et al., 2010; Jirapaet, 2000; Johnson et al., 2015; M. S. Miles et al., 2003; Mitrani et al., 2010; Murphy, Armistead, et al., 2011; Nelms & Zeigler, 2008; Oswalt & Biasini, 2011; Rotheram-Borus et al., 2001; Rotheram-Borus et al., 2003; Rotheram-Borus et al., 2012; Rotheram-Borus et al., 2011). The findings from this study offer insights and guidance for health practitioners to consider regarding the social systems of oppression at work in the lives
of their patients, the possible frames of interpretation the mothers may be using to navigate those social relationships, the power differentials and structures that shape their clinical encounters and the potential health implications of each of these elements. The findings support strength-based approaches to clinical management, approaches acknowledging the centrality of motherhood, and other specific process level interventions warranting further examination such as animal-assisted therapies. Finally, I assert that the findings from this study bolster a recent movement to turn health practitioner education away from pedagogic approaches that emphasize cultural competency to ones that underscore structural competency in addressing stigma and health inequality (Metzl & Hansen, 2014).

4.9.7 Implications for Research

Further research is needed to expand and test the conceptual framework and in particular the propositions suggested by relationships between intersecting determinants and health outcomes. In this study, I found that certain social determinants appear to be mutually constituted and others are opposing. Research is needed to explore the relationships among the intersecting social determinants of health, health care access indicators and quality of health care indicators using robust quantitative data analytic techniques such as mediation, moderation and system science, dynamic approaches. Additionally, it will be important to establish
community-advisory group(s) to disseminate the findings from the study and identify
further potential analytic lines for inquiry.

4.9.8 Conclusion

The social location and health experiences of African American mothers living
with HIV operates at the intersection of gender-, race- and class – inequality; HIV-
related stigma; and motherhood and mothers develop frames of interpretation to
navigate those social relationships and power differentials. A great deal of work is
needed to imagine, construct, test and build the body of evidence for the structural
interventions needed to impact these social structures and health inequality through
policy, law and practice.
5. Dissertation Conclusion

Focused attention on the needs of mothers living with HIV, in addition to elimination of maternal to child transmission, has only recently gained momentum on the global stage (UNAIDS, 2011). Prior strategies have focused on time-limited interventions provided during pregnancy and breastfeeding, rather than on longitudinal approaches aimed at meeting the needs of mothers over time (CDCP, 2012). Yet, we know that keeping mothers living with HIV healthy and in care has far-reaching health and developmental implications for mothers, their children and families (M. S. Cohen et al., 2011; Murphy et al., 2012; UNAIDS, 2011). Beyond the prevention of maternal to child transmission, however, the number of interventions targeted to mothers living with HIV is relatively small and studies of interventions are limited by subject attrition such as residential instability (Futterman et al., 2010) and HIV-related stigma (Black & Miles, 2002; M. S. Miles et al., 2003). In addition, most of the interventions aimed at persons living with HIV have focused on individual risk behaviors rather than the social determinants of health, and while important, individual risk behaviors only partially explain health outcomes (Adimora & Auerbach, 2010; Arrington Sanders & Ellen, 2010; Lane et al., 2004). The magnitude of the disease burden and disparity in health outcomes for African American mothers living with HIV are clear across racial (CDCP, 2013, 2015), gender (CDCP, 2014a) and
socioeconomic groups (CDCP, 2010b; Elmelech & Lu, 2004; U.S. Census Bureau, 2012) and of particular concern. Understanding the intersection of gender-, race- and class-inequality; HIV-related stigma; and motherhood is essential to address the disparate health outcomes of African American mothers living with HIV. No other studies have explored and described how social determinants intersect and influence the health experience for these mothers and this dissertation work yielded several important discoveries toward that end.

The health experiences of African American mothers living with HIV are fashioned by a complex configuration of social inequalities and structural barriers as well as individual strengths and vulnerabilities, but the specific ways in which they intersect for this population has been unclear. Participatory research methods have helped to reveal the temporal aspects and heterogeneity of these complex intersections as well as the individual responses of participants to their specific social locations despite the similar demographic profiles. Using participatory methods with a highly stigmatized and vulnerable population of women was not without its methodological and ethical challenges, however, and navigating these challenges yielded important findings about the reflexivity and flexibility required in the research process. The configuration of social determinants of health for African American mothers posited in the conceptual model Motherhood and HIV: An Intersectional Approach (Caiola et al.,
2014) proved to be a valuable resource in beginning to conceptualize how social
determinants intersect to influence health experiences for this population. In addition to
describing the configuration of social determinants posited in the model, this
dissertation research also refined the components of the model and analytic techniques
for intersectional approaches that may be replicated in further health equity research.

5.1 Conceptual Model of Motherhood and HIV: An Intersectional
Approach

Findings from a literature review revealed that prior to the release of the 2011
Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and
Keeping their Mothers Alive (UNAIDS, 2011), there are few interventions specifically
aimed at improving health outcomes for mothers living with HIV and reaching beyond
just the prevention of maternal to child transmission (Davies et al., 2009; Futterman et
al., 2010; Glover et al., 2010; Jirapaet, 2000; M. S. Miles et al., 2003; Mitrani et al., 2010;
Murphy, Armistead, et al., 2011; Nelms & Zeigler, 2008; Oswalt & Biasini, 2011;
Rotheram-Borus et al., 2001; Rotheram-Borus et al., 2003; Rotheram-Borus et al., 2011).
The release of the global plan has spurred more interest in this area of international
importance, with many interventions being tested at the global level, and far fewer
interventions studies noted in the United States during this time recent time frame
(Johnson et al., 2015; Rotheram-Borus et al., 2012). Of those introduced domestically,
each focused on health behaviors resulting in mixed success. Further examination of the literature revealed that the social determinants of health and potential structural interventions to impact the health of persons living with HIV are gaining recognition (Adimora & Auerbach, 2010; Adimora et al., 2014; Arrington Sanders & Ellen, 2010), but no studies have described the intersecting structural barriers and social determinants of health specific to African American mothers living with HIV as the foundation to intervention work. Thus, the major implication of the literature review was that exploratory, descriptive research was needed to investigate two major research aims: (1) describe the specific social location of African American HIV-infected mothers and their mutually constituted social identity at the intersection of gender-, race- and class – inequality; HIV-related stigma; and motherhood; and (2) explore the ways in which the unique social identity of African American HIV-infected mothers influences their health-related experiences.

A new conceptual model, Motherhood and HIV: An Intersectional Approach (Caiola et al., 2014), was developed to guide this exploratory research. With a basis in the intersectional work of African American feminist and social scientists (Hankivsky, 2012) and other frameworks examining vulnerable populations (Shi & Stevens, 2010), the new model facilitated the conceptualization of the qualitative descriptive approach needed to explore the intersection of gender-, race- and class- inequality; HIV-related
stigma; and motherhood for African American mothers living with HIV. In addition, the conceptual model guided the research implementation, including the selection of subjects, data collection methods, categories for the structural coding and analytical approach using vector and frame analyses.

5.2 Participatory Methods and Reflexivity

The exploratory nature of this dissertation and the intersectional approach used to develop the conceptual model were particularly influential in the selection of participatory data collection methods of in-depth interviewing, photo elicitation and storyline graphs. Intersectional approaches are steeped in both scholarship and activism in the pursuit of social justice; so participatory research methods, participant-researcher collaboration and community engagement are well-matched with the approach (U. A. Kelly, 2009; McCall, 2009). Using participatory methods with a highly stigmatized and vulnerable population of women, however, posed several methodological and ethical challenges. Piloting the interview guides and photo elicitation method with a small group of participants helped to refine the guiding interview questions, establish the feasibility and utility of the photo elicitation methods, and also reveal some of the ethical challenges specific to using visual methods with this population. The greatest concern was and continues to be breaches in privacy, confidentiality and/or unplanned disclosures of a participant’s HIV status. To my
knowledge, there were no such breaches or disclosures, and in the interest of minimizing any risk I will continue to draw on the best practices born from the pilot work as well as continue to use a high degree of reflexivity while disseminating the findings. Finally, the pilot work provided rich data about potential analytical lines that I then pursued further with the rest of the sample.

5.3 Intersecting Social Determinants of Health

The configuration of social determinants of health for African American mothers posited in the conceptual model Motherhood and HIV: An Intersectional Approach (Caiola et al., 2014) proved to be a valuable resource in beginning to conceptualize how social determinants intersect to influence health experiences for this population; with gender-, race-, class- inequality and HIV-related stigma most commonly acting as mutually constituted vulnerabilities while motherhood varied more considerably as either a vulnerability or strength. Considering the experiential aspects of daily life with HIV also broadened the findings and helped to illuminate temporal aspects, context-dependent constructions, power structures and heterogeneity of the complex intersection of social determinants as well as the individual responses of participants to their specific social locations; thus, further substantiating the needs for structural interventions to alter the social context in which these mothers make health decisions. The vector and frame analysis provided empirical evidence of the
heterogeneity of individual responses to social location and proposed three potential frames – emancipatory, situational and internalized - from which to develop testable hypotheses about typologies of vulnerability that may be relevant for clinicians and policy-makers.

**5.4 Conceptual and Analytic Refinement of Intersectional Approach**

The findings helped to refine the components of the intersectional model and analytic techniques for intersectional approaches that will be important for future research. Six social determinants of health – social support, religiosity, animal companions, physical environment, transportation and housing – that were not included in the intersectional model developed for the study were identified by participants, each worthy of further investigation for their role in the health experiences and outcomes of African American mothers living with HIV. Four out of the six determinants identified by participants were deemed positive social determinants of health and provided a case for the potential value in developing and testing more strengths-based approaches to health research and practice with persons living with HIV. The finding that social determinants act as mutually constituted strengths and opposing determinants in addition to mutually constituted vulnerabilities also conceptually broadened the initial model and “social location” rather than “mutually constituted vulnerability” may be the more appropriate representation at the center of
the model.

The analytic techniques developed for this study also offer an alternative to some of the methodological complexities of executing an intersectional approach or moving it from theory to praxis. The vector analysis, adapted from a Vector Model of Complexity, offers a means of conceptualizing and visualizing the configuration of social determinants for individual study participants, which in turn made possible a broader comparative analysis across cases in the frame analysis.

5.5 Limitations

The generalizability of the findings of this study may be limited by selection bias, study attrition, and research protocol differences across study phases. All participants were recruited either because of their prior involvement in HIV research examining the efficacy of a stigma reduction intervention or from infectious disease clinics. Thus the participants in this study may have higher levels of internalized stigma than the general population of persons living with HIV or may not represent the experiences of person living with HIV who are not engaged in care. Study attrition, meaning those mothers not completing all three interviews, was high at 21% and impacted the number of cases for which I was able to fully complete with vector and frame analyses. The intentional phased study approach developed so that the visual methods protocol could be sufficiently piloted, resulted in a slightly different research
protocol being implemented across the sample (Figure 40), which in turn impacted the number of storyline graphs I was able to construct and the photographs participants were allowed to produce as data.

Table 11: Research Protocol Variations

<table>
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<tr>
<th>Research Protocol</th>
<th>Participants Involved</th>
<th>Total Number of Participants</th>
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<tr>
<td>Photographs with no identifiable persons</td>
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<tr>
<td>Photographs including mothers and children</td>
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5.6 Implications for Practice

The findings from this study offer insights for health practitioners to consider regarding the social systems of oppression at work in the lives of the people they care for and the power differentials and structures that shape their clinical encounters. The proposed frames for social location – emancipatory, situational, internalized – offer typologies that may be clinically relevant for clinicians as they consider the trade-off decisions their patients make as they consider health care decisions and some of the
potential health implications of the frames themselves (Safford et al., 2007). The hypothesized frames, once tested, may also offer evidence for developing tools to guide clinicians in helping African American mothers living with HIV to make health care decisions (Caiola et al., 2014; Safford et al., 2007). The findings also substantiate the recommendation for strength-based approaches to clinical management and other specific process level interventions mentioned such as animal-assisted therapies. Finally, I would assert that the findings from this study underscore the need to move from cultural competency approaches in nursing education to ones that underscore structural competency in addressing stigma and health inequality (Metzl & Hansen, 2014).

5.7 Implications for Research

Future research is needed to explore and test the relationships among the intersecting social determinants of health, health experiences and health outcomes as proposed in the conceptual model for mothers living with HIV. Understanding the relative contributions of each of the vector determinants on mothers’ health experiences and subsequent health outcomes will require further exploration into robust quantitative and qualitative data analytic techniques to examine these factors (Safford et al., 2007). The conceptual, methodological and analytic approaches utilized in this study expand current thought; however, significant challenges in executing
intersectional approaches remain. In particular, additional innovative approaches that facilitate participant engagement and trust are important so that the nuances of the social location of these mothers can be fully understood. Likely this will require significant cooperation and collaboration between multidisciplinary teams that can offer the strengths and diversity of approaches needed to address such complexity.

5.8 Conclusion

The health experiences of African American mothers living with HIV are fashioned by a complex intersection of gender-, race-, class-inequality, HIV-related stigma and motherhood; as well as other potentially significant social determinants identified in the study findings. The findings from this study suggest further investigations should evaluate and test how these social forces operate to shape health behaviors and produce health outcomes for African American mothers living with HIV such that process level and structural level health interventions can be developed to improve the overall health and well-being of mothers living with HIV and their family members.
Appendix A. Recruitment Letter to Participants

Address of potential participant

[Date]

Dear Ms. :

I am writing to you because you have been participating in a research study that is being done by Courtney Caiola at the Duke School of Nursing. I am supporting Courtney in this study and providing oversight to her work.

Courtney has been attempting to contact you by phone to schedule two more interviews to discuss any pictures you have taken with the disposable camera she gave you. She is more than willing to meet you at your home or give you a bus pass to the Duke School of Nursing or the North Carolina Mutual Building where the interviews will occur. Unfortunately, she has been unable to reach you.

Participation in research is voluntary. If you choose to participate, you are also free to withdraw from the study at any time.

I have valued your participation in my research in the past and your input has been very important. If you are interested in continuing with the study, I encourage you to contact me, Dr. Julie Barroso, at 919.684.9341 during regular business hours. We will not contact you again unless you call me to indicate your interest. Thank you for considering this request. Please do not hesitate to contact me if you have any questions or concerns.

Sincerely,

Julie Barroso, PhD, ANP, APRN, BC, FAAN
Professor, Duke University School of Nursing
Appendix B. Screening Tool

Date of Birth: ___________ (must be prior to November 1994)

Do you have HIV? Yes/no (must report “yes”)

What is your race? (must report Black/African/African American)

Do you have dependent children between the ages of 0-18 years old residing in your home? Yes/no (must report yes)

If yes, how many? ______

Are you eligible for public assistance or Medicaid? Yes/No (must report yes)
Appendix C. Sociodemographic Assessment Form

Subject Number: ___________
Enrollment Date: ___/____/____

What is your gender? _____
1 = Male
2 = Female

What is your date of birth? ___/____/____

Which racial group best describes you? _____
1 = White or Caucasian
2 = Black or African American
3 = American Indian or Alaskan Native
4 = Asian or Pacific Islander
5 = Multiracial
6 = Other

What is your marital status? _____
1 = married
2 = single/never married
3 = not currently married/widowed
4 = not currently married/divorced
5 = cohabitating with long term partner

How many years of education have you had? _____
(Enter 12 for high school diploma or equivalent, 16 for bachelor’s degree, 18 for master’s degree, 20 for doctoral degree)

Are you currently employed? _____
1 = yes
2 = no

What is your total monthly income from all sources, including other family members living with you (housemates do not count)? ______________

Number of dependent children, between the ages of 0-18, residing in your home? ______

Please give their ages: __________________________

How many years ago did you contract HIV? ______

How do you think you contracted HIV? _____
1 = Sex with a man
2 = Sex with a woman
3 = Injection drug use
4 = Blood transfusion
5 = Occupational exposure
6 = Other (Please describe:______________)

How would you describe your sexual orientation? _____
1 = Heterosexual
2 = Gay
3 = Lesbian
4 = Bisexual
5 = Other (Please describe:______________)

What is your most recent CD4 (T cell) count? ________

What is your most recent HIV viral load? ________(Range = undetectable to 750,000)
Are you currently taking antidepressants or medications to treat depression? ______ 1 = yes 2 = no

Are you currently taking other medication for mental health problems? ______ 1 = yes 2 = no

Have you been diagnosed with any other chronic health condition? ______
(List all that apply)
1 = No
2 = Hypertension/High Blood pressure
3 = Diabetes
4 = Arthritis
5 = Hepatitis B
6 = Hepatitis C
7 = Other (Please describe:______________)

Are you currently taking antiretrovirals to treat your HIV? ______ 1 = Yes 2 = No
Appendix D. Rapport Building Interview Guide

Question 1: Please tell me about your experience of being a mother living with HIV.

Probes:

1. How does having HIV impact your ability to mother?
2. How does being a mother impact your ability to take care of your health and manage your HIV?
3. What gives you pleasure in caring for your child(ren)
4. What has been the most difficult aspect of caring for your child(ren)?

Question 2 (Storyline Graph): Please tell me about the key events in your life as a mother, when they occurred (date and/or age), and how you felt about them.

Question 3 (Storyline Graph): Please tell me about the key events of living with HIV, when they occurred (date and/or age), and how you felt about them.

Field Notes:

 Record information describing the interview experience, including any impressions or events that occurred during the interview.

Length of Interview:

Where did interview take place?

Who was present during interview other than the mother? Her child(ren)?

Describe any interruptions that occurred.

Describe the mother’s emotional and/or physical state during interview.

Describe any observations or reflections that you have about this interview that you feel are relevant to the analysis of this interview.
Appendix E. Goals and Use of Participant-Initiated Photography

Goal One:

To picture or capture the social and economic experiences of your daily life which negatively impact your health or ability to care for your HIV.

Goal Two:

To picture or capture the social and economic experiences of your daily life which positively impact your health or ability to care for your HIV.

Brainstorming Activity:

Visualize or think about something in your surroundings/home/environment/community that negatively impacts your health or ability to care for your HIV. What/who is it and can you take a picture of it?

Visualize or think about something in your surroundings/home/environment/community that positively impacts your health or ability to care for your HIV. What/who is it and can you take a picture of it?

Visualize or think about how money/your finances/your resources negatively impact your health or ability to care for your HIV. Can you take a picture of that?

Visualize or think about how money/your finances/your resources positively impact your health or ability to care for your HIV. Can you take a picture that?

Ethical Issues:

Please do not take a picture of anyone including yourself or your children.

Any pictures developed containing images of persons will be shredded according to the study protocol. Only take pictures or use the camera in situations in which you feel comfortable that your confidentiality can be maintained.

Demonstration of Camera Use:

Each participant will be given a disposable digital camera with at least 27 exposures for the study.

Demonstration and return demonstration of the camera features will be conducted and include use of the flash.
**Return of Camera to Study Coordinator:**

The participant will receive an addressed and stamped envelope to return the camera to the study coordinator via the US Mail.

The participant will be given 3-6 weeks to take photographs and the return date will be established and written down for participant.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

**Length of Interview:**

Where did interview take place?

Who was present during interview other than the mother? Her child(ren)?

Describe any interruptions that occurred.

Describe the mother’s emotional and/or physical state during interview.

Describe any observations or reflections that you have about this interview that you feel are relevant to the analysis of this interview.
Appendix F. Photograph Content Interview Questions

The participant will receive a copy of her photographs that she may keep. The study coordinator will also retain a copy of the photographs. The participant will be asked to select the photographs that she feels most represents the social or economic issues impacting her health and talk about them using a framework modified from the SHOWeD framework utilized in the Photovoice:

What do you See here?
What is really Happening here?
How does this relate to your health/life?
Why does this situation, concern or strength exist?
What can we Do about it?

The content from the SHOWeD data will then be used to identify themes, vulnerabilities and strengths of the participant’s respective life story.

Field Notes:

Record information describing the interview experience including the number of any photographs described and the order in which they are described. Any impressions or events that occurred during the interview.

Length of Interview:

Where did interview take place?

Who was present during interview other than the mother? Her child(ren)?

Describe any interruptions that occurred.

Describe the mother’s emotional and/or physical state during interview.

Describe any observations or reflections that you have about this interview that you feel are relevant to the analysis of this interview.
Appendix G. Final In-depth Interview Guide

The mothers will be asked open-ended questions to explore the intersection of gender-, race-, class- inequality; HIV-related stigma; and motherhood.

Question 1 (gender):
What goes through your mind when you think about your experience of being a woman living with HIV?
- Have you ever experienced discrimination because you are a woman?
  - If yes, how do you think those experiences impact your health? Caring for your HIV?
  - If no, how does being treated equally to men impact your health? Your ability to care for your HIV?

Question 2 (race/racism):
What is it like being an African American mother?
- Have you ever experienced discrimination because of your race?
  - If yes, how do you think those experiences impact your health? Caring for your HIV?
  - If no, how does being treated equally to other races impact your health? Your ability to care for your HIV?
  - What is it like being an African American mother living with HIV?

Question 3 (SES):
Have you ever experienced discrimination because you live with a limited income?
- If yes, how do you think those experiences impact your health? Caring for your HIV?
  - If no, how does having enough financial resources impact your health? Your ability to care for your HIV?

Question 4:
How do you think others treat you as a mother living with HIV?
Have you ever experienced discrimination because you are a mother living with HIV?
- If reports being stigmatized -
  - Can you please describe your experience?
  - How have such experiences influenced you seeking treatment for your HIV?
  - How have such experiences influenced you caring for your HIV?
**Question 5:**
Have you told your children about your HIV infection?
   If has disclosed:
   Have your child(ren) experienced discrimination by others because of your HIV infection?
   If has not disclosed:
   Why have you chosen not to disclose your HIV status to your children?

**Question 6:**
Which, if any, of these things [being a sexism, racism, classism, stigma, motherhood] pounds away at you the most? Which makes it most difficult for you to care for your health?

**Question 7:**
Which, if any, of these things [being a woman, being African American, your financial resources, motherhood or how people treat you because you have HIV] lifts you up the most? Which really helps you to take of your health?

**Question 8:**
If you could give advice to another mother living with HIV about taking care of her health and her HIV – what would you say?

**Question 9:**
How do you define health? Based on your own definition, do you consider yourself healthy right now?

**Field Notes:**
Record information describing the interview experience, including any impressions or events that occurred during the interview.
   Length of Interview:
   Where did interview take place?
   Who was present during interview other than the mother? Her child(ren)?
   Describe any interruptions that occurred.
   Describe the mother’s emotional and/or physical state during interview.
   Describe any observations or reflections that you have about this interview that you feel are relevant to the analysis of this interview.
Appendix H. Storyline Graphs

![Storyline Graph: Participant 006](image)

30 yo - diagnosed with HIV while in jail; also struggling with drug addiction, stated “I don’t think I actually had a feeling. It was just something that was said” (Interview 1)

43 yo - diagnosed again while in jail and began follow up with the locale health department

48 yo - began medication; reported no change in physical health and stated “to tell you the truth, I don’t feel no different now than I did then.” (Interview 1)

52 yo - became the guardian to her niece and nephew; recalled “…didn’t want to accept it, but had to.” (Interview 1)

53 yo - current perception of living with HIV; reported being “at peace” with her HIV diagnosis and says the peace is very much a positive (Interview 1)

53 yo - current perception of motherhood; Stated it was her most positive social determinant of health and said, “…just make sure that they are two happy children. You know and if they’re happy I’m happy, so yeah.” (Interview 3)

Figure 40: Storyline Graph Participant 006
20 yo - Missed miscarriage secondary to incompetent cervix: “The worst one [pregnancy loss] to me was the very first one” (Interview 1)

30 yo - Diagnosed with HIV and recalled, “But when I found out, I was shocked. Not that it couldn’t happen to me, I was just shocked that no, not me.” (Interview 1)

32 yo - Became a stepmom; reported, “With my stepdaughter I guess to know that she accepts me as the same. The same way she does as her biological mom. She calls me mom.” (Interview 1)

33 yo - Started on HAART and stated “I was devastated. I was very upset.” (Interview 1)

35 yo - Delivered Trisomy 21 child that died

37 yo - Blighted ovum

39 yo - Current pregnancy; progressing normally and reported “Just excited about being a first time mom.” (Interview 1)

39 yo - When asked if her HIV will impact her motherhood she stated, “And motherhood it doesn’t affect… I don’t think it will affect it. I mean not at all,” and with regards to the HAART she stated, “But, it’s better now. It’s much better.” (Interview 1)

Figure 41: Storyline Graph Participant 008
18 yo - Delivered 1st child; described that it was an "okay experience, but it was kind of stressful" because the father of the baby was not involved and she was young (Interview 1)

23 yo - Delivered 2nd child; reported it was better because she had learned how to be a single parent; but also reported more difficulty raising a girl and concerned about the unsafe neighborhood they lived in (Interview 1)

27 yo - Delivered 3rd child; described as "it was a piece of cake 'cause I was married, I was twenty seven years old, I had all the help I needed, I didn’t have to work. (laughs) It was just great having the father in the home while I carried him continue raising him." (Interview 1)

27 yo - Diagnosed with HIV during her 3rd pregnancy; described as "stressful," primarily because the medications made her feel ill and she was concerned the infant would be HIV positive (Interview 1)

36 yo - Current perception of motherhood; reported difficulty hiding her serostatus from her children and stated it was difficult. "Hiding the whole situation." She is also concerned about raising her children in their neighborhood, "So that's part of the reason why she's with her father now because this is really not a good neighborhood and I don't want her to come up here. I would like for her to be in a safer environment with much better surroundings." (Interview 1)

36 yo - Current perception of living with HIV; stated, "No I mean since I had it for seven years now, I figure I'll be here even longer. You know it's a lot of stress since I've been educated more about the virus and I know that if you take your medication you can live a long, happy life. So it's not the end of the world like I thought it was when I was diagnosed so." (Interview 1)

Figure 42: Storyline Graph Participant 009
16 yo - Delivered 1st and only child; stated "I was excited" (Interview 1)

17 yo - Diagnosed with HIV; stated "And I just started crying, broke down, like it took the breath out of me and I was distraught. And I was suffering from depression then but I hadn't ever been diagnosed from it, for it, I was depressed real bad. I couldn't take a bath, And I know my daughter could tell...it just took something out of me and I couldn't even look at her I was so embarrassed, so ashamed." (Interview 1)

19 yo - Reported that she started using drugs; stated "So, as time went by, I just felt like I was an outcast or something so I started getting high, I started doing drugs...And it was just like a big turn in my life. It did something to me. (Interview 1)

28 yo - Pivotal health event - diagnosed with AIDS; got clean from drugs and started HAART (Interview 1)

30 yo - But, from then to now I'm a whole other person because for one, you can live, you die because you want to die your body shut down because you allowed it to shut down you know? You got to make that decision to want to live. Can't nobody live for you but you. (Interview 1)

30 yo - With regards to motherhood now stated, "Don't never stop believing, that's the advice I have for the mothers keep believing. Something good going to always come your way just continue to believe, never give up on yourself and definitely stay strong for your children. At the end of the day they need you," and "the best I can do right now is just try to be a good parent." (Interview 1)

Figure 43: Storyline Graph Participant 010
19 yo - Delivered 1st child; stated that she was "overwhelmed" and she "wasn't ready" (Interview 1)
25 yo - Delivered 2nd child; with regards to this pregnancy she stated she, "kept saying I wasn’t going to have any more kids” (Interview 1)
35 yo - Delivered 3rd child; with all her pregnancies she "...prayed I want a boy. I want a boy. Don’t want little girls." (Interview 1)
35 yo - diagnosed with HIV during 3rd pregnancy, stated, ”I felt floored.” (Interview 1)
36 yo - 3rd child diagnosed with Kawasaki’s disease and very ill and described by saying “So it floored me. I was crying in the emergency room. They had to bring social workers. All kind of stuff ‘cause they was like ‘Mama we’re going to need to you calm down.’” (Interview 1)
39 yo - became homeless with her sons
40 yo - 2nd child diagnosed with Aspers and stated, "I was fighting for that for a long time." (Interview 1)
41 yo - reported she had not disclosed to her children or anyone and that was difficult for her, but that “I actually feel like I go even harder for them knowing my diagnosis” (Interview 1)
41 yo - current perception of HIV, "I don’t know how to describe to people I’m not dying I’m living. I don’t know about y’all. I might out live some of y’all, but everyone has that stigma of HIV even myself included in the beginning cause I’ve had patients that were HIV positive and I was with them for years. So I know people can go on. There’s just some people who they either were never diagnosed or were not diagnosed in time so they couldn’t get the viral load up. Thank God I did what I had to do. (Interview 1)

Figure 44: Storyline Graph Participant 011
15 yo - Delivered 1st child; "I was excited to be a mother" (Interview 1)
16 yo - Delivered 2nd child; stated, "Well after my first one I didn’t want no more babies because I had it natural. But [name] came along, you know what I am saying?" (Interview 1)
[Later revealed these pregnancies were a result of child molestation/statutory rape]

24 yo - Diagnosed with HIV; reported, "I was suicidal." (Interview 1)
55 yo - Identified motherhood as her most positive social determinant of health (Interview 3) but also reported, "Well it depends how - I mean I guess its [motherhood]stressful to me" (Interview 1)

55 yo - Current perception of HIV; stated "Well ah- I know I can’t get rid of it. (P crying) It ain’t my fault. That’s the question I keep asking God, ’What did I do so wrong to get this-that this happened to me?’ But I’m living with it. I’m living with it. I get so frustrated cause sometimes I forget I ain’t normal...And what really bothers me…” (Interview 1)

Figure 45: Storyline Graph Participant 012
20 yo - Delivered 1st child; did not assign emotional value.

23 yo - Diagnosed with HIV during a pregnancy that she ultimately miscarried; stated “I didn’t want to live. I really didn’t.” (Interview 1)

28 yo - Delivered 2nd child; stated “I didn’t want to be pregnant with him...” (Interview 2)

29 yo - Delivered 3rd child; stated she “was not ready for another baby” (Interview 1)

30 yo - Reported recent positive events and feeling proud of her oldest daughter (track and field and cheerleading); also reported excitement when her second child recently started walking; described her two youngest children as “miracle babies” for being HIV negative. (Interview 1) Current perception of motherhood stated, “It might be hard but I think we live for our little ones.” (Interview 3)

30 yo - Current perception of living with HIV stated “So I say- you know it’s only been about a few years ago but you know I started saying, ‘it’s a reason to live.’ And like I said, there’s a reason for everything. There is a reason why I’m still here. So I just look at it like I’m living life to the fullest, that’s what I’m doing.” (Interview 2)

Figure 46: Storyline Graph Participant 013
21 yo - Delivered 1st and only child; described event by saying, "...my playtime was over" (Interview 1)

21 yo - Diagnosed with HIV during the pregnancy and reported "it was devastating...it was a blessing to have him but...finding out all at one time its like overwhelming" (Interview 1). Described time further by saying "Yeah, I was torn between the emotion like happy but sad at the same time" (Interview 1)

30 yo - Current perception of motherhood, "...it makes me happy." (Interview 1) and she described her son as a motivation to care for herself and her health.

30 yo - Described starting on HAART as a difficult time and described it by saying, "But I'm like, Why I gotta take medication?" Like I gotta fight even harder just to make sure everything's okay. You know what I'm saying?" (Interview 1) but also described her current perception of living with HIV in this way. "I feel like I'm surviving like um, um, I can make it. You know if I made it this long I can keep going on you know what I'm saying? So I feel like motivated, like I gotta do- I gotta enjoy life. Don't let it get to me." (Interview 1)

Figure 47: Storyline Graph Participant 016
32 yo - Diagnosed with HIV; stated, "I was devastated when I found out" (Interview 1) and further stated, "Yeah, it was a death sentence for me..." (Interview 3)

42 yo - Became the guardian of her great niece; this was prior to her current health issues and leg amputation; stated, "At first it wasn’t as difficult as it is now because I could walk at the time" (Interview 1)

46 yo - Current perception of HIV, "you learn to get over it" (Interview 1) and "it’s just something that happened, it wasn’t meant to happen, it just happened." (Interview 3)

46 yo - Current perception of motherhood "It feels real good. It really does. I have more responsibility to not want to use" (Interview 1); participant is recovering drug addict

Figure 48: Storyline Graph Participant 017
18 yo - Delivered 1st child; stated ", when I was pregnant with my first son I was -- I was happy and sad at the same time because I found out I was positive..." (Interview 1)

18 yo - Diagnosed with HIV during pregnancy; stated, "...I was devastated. I was sad and I just felt like I couldn’t live anymore." (Interview 1)

19 yo - found out first child was HIV negative; stated "...when I learned that you know he was not positive...I was elated" (Interview 1)

23 yo - Described a period at this age when she was a single mom and reported it was a "difficult" time (interview 1)

26 yo - Current perception of HIV: "Well my self esteem has gotten much better about it now. Now I have my husband, a good support system to help me cope everyday." (Interview 1)

26 yo - Current perception of motherhood; " My children are a a blessing so that’s even better to move forward and get me a reason to move forward." (Interview 1)

**Figure 49: Storyline Graph Participant 018**
NOTE: Did not chose to talk about her older children
34 yo - Delivered her youngest child, stated, "The most important is when I was was hoping that my daughter wasn't HIV. that's first off. And from there we took it one day at at a time." (Interview 1)
34 yo - Diagnosed with HIV during pregnancy of youngest child, stated, "Oh, I felt sad. I cried. Oh boy, life was gonna end." (Interview 1)
35 yo - Reported quickly adapting emotionally to HIV diagnosis; stated, "...after about a couple months when I got my right medication...they helped me push myself and after that life went on just beautiful." (Interview 1)
49 yo - Current perception of motherhood; "Oh, I'm the best mom on the earth." (Interview 1); went on and described
And we are happy, we're not everyone knows like in my family, like my immediate family. And we just take it one day at a time. We are happy, we're not 'oh well, my mom has this, oh. No.' " (Interview 1)
49 yo - Current perception of living with HIV; "Yep, life just goes on, like I said one day at a time. Okay, you just wake up smiling, I'm happy to be here." (Interview 1)

Figure 50: Storyline Graph Participant 019
Appendix I. Intersection of Social Determinants

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<th>Intersection Determinants</th>
<th>Exemplar Quotes</th>
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<tr>
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<td>P:...I don’t know if I can really answer that because...being a woman with HIV for me I would say it’s different because I’m a mother. So...I guess it impacts me as far as my children and the concern and stuff like that um, so I would say yeah it’s different for me you know, as far as the aspect of being a mom and trying to raise the children that I have. And...I guess my answer is just yes. [laughs]. Being a mom it’s different. Because the man, he can go about his business you know and most of them are you know?[Being a mother] makes it different because it makes you want to take care of yourself even more, you know, to be here for your children, to school them, about this disease. Um...’cause nowadays you know the young people are just running around sleeping with this one and that one and not really having concern about protecting themselves. So you know just being a mom and trying to be here for my children makes it better for me. (Participant 3, Interview 3)</td>
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<tr>
<td>Class/Race/Motherhood</td>
<td>Participant asked to describe what it is like to be an African American Mother.</td>
<td>Mutually Constituted Vulnerability</td>
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<td>Um well, it is a struggle. Um for one thing it is a lot of still a lot of prejudice going on ever though sometimes it’s not as visible as it used to be. Um even in politics today, this man that’s running against Obama you can tell he’s not for the poor and the um midclass families. He’s only for the rich because he wants to cut out everything for the poor folks, well for the middle class families...And looking at that itself is really a struggle ‘cause you’re having to, as my grandmother would say ‘you had to steal from Paul in order to pay Peter’...and you may not have to do it all the times, but you you try to figure out ways that you can cut back on certain things so you can, the little money that you do have, you can stretch it out. And not only with that in case any activity say anything come up for the children you sho’ enough you got to rob Paul to pay Peter in order to look out for them. (Participant 6, Interview 3).</td>
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| **Motherhood/Class**  
Participant asked to describe the most difficult aspect of caring for her child | And it’s like some days I just want to give up because it’s hard you know. My financial situation, I’m trying to find a job you know just different things. It’s like barriers with me raising her you know but I try to set a good example for her you know. That’s all I can do right now is just be a good role model and tell her right from wrong you know and from my experience, the hands on experience, to let her know that all things ain’t cracked up to what you think they are, what this thing is to be, and that’s the best I can do right now is just try to be a good parent. (Participant 010, Interview 1) | Mutually Constituted Vulnerability |
|---|---|---|
| **Motherhood/Class**  
Participant asked to describe the most difficult aspect of caring for her children and grandchildren | Well, not- not getting them what they want and stuff when they be asking me and I don’t have it to give them. It breaks my heart, like granddaughter name might have a school trip going on and stuff like that I might not have the money to get it for- she want pictures and stuff I can’t afford to get her pictures. I’m on a set- income or she might want some shoes. I can’t afford to get it for her. I go get secondhand. It bothers her, but she wears them. She likes to have something new sometime. Like Christmas, I didn’t too much. I was sick I couldn’t go out and sign ’em up for Christmas so I don’t know what I’m gonna do about Christmas. I just, mm-mm... She’s getting taller and she really skinny and tall. Her pants getting shorter and I got to do what I got to do. (Participant 012, Interview 1) | Mutually Constituted Vulnerability |
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<th>Motherhood/Class/Race</th>
<th>Participant asked to describe being an African American mother</th>
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<td>**Oh my God, it's hard. Especially when you're trying to raise your grandkids and trying to give them the best. You know kids sees these other kids with good stuff and it breaks my heart that I can't give them- I mean not- nothing expensive but at least- you know what I'm saying?...Um, then um, you got to deal with the teenage- when they get to the teenagers- cause they want to do what they want to do and not listen and stuff and then I got to deal with my illness and then with them. So ah, what do I do about that? My grandkids know about me and they respects me. ‘Cause I take privileges away and let them know that um, things they do is not right you know? As long as they under my roof, they got to abide by the rules. But it's real hard on me like um, I have to go to the food bank... So I just- I get $67 in food stamps and ah, I go to a lot of food banks and then that's how I survive when it comes to food. I go to a lot of thrift stores and a lot of churches to get clothes for them, which I know they don't like it but I try to find the good ones. Um, it's hard you know what I'm saying? I'm more of a loner. I mean I'm a people person when I go out there in the world. But I'm a loner; you know what I'm saying? ‘Cause on the outside it might look- but on the inside it's just so much broken pieces of glasses inside of me. So I told ‘em if I'm getting at Christmas when I get my check next month- January I'll buy them something. Cause I have to pay my bills. (Participant 012, Interview 3)</td>
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<td><strong>Motherhood/Class</strong></td>
<td>Participant asked to describe the most difficult aspect of caring for her children</td>
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<td><strong>Motherhood/Class</strong></td>
<td>Participant asked to describe the most important aspects of being a mother</td>
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<td><strong>Motherhood/Class</strong></td>
<td>Participant asked to describe the most difficult aspect of caring for her child</td>
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<td><strong>Motherhood/Class</strong></td>
<td><strong>Participant asked to describe key moments as a mother</strong></td>
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<td><em>Um, just like growing up like basically around him I had to grow up. I had to make hard decisions. I had to do all I can and you know taking care of him I had to you know it's hard to keep a job. Cause you work in retail and then sometimes it comes and goes like financially it's a lot. (Participant 016, Interview 1)</em></td>
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<td><strong>Motherhood/Race/Class</strong></td>
<td><strong>Participant described difficulty accessing social services and it impacts on her health</strong></td>
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<td><em>Yes, it stresses me out. I uh, like uh- we didn’t have no food here and ah, one day I went to the food bank –Mexicans was there but the same day as mine on the 25th- I can go in the food bank, I went on the 24th, but I seen this Mexican voucher was the 25th, like mine. They let her go through and wouldn’t let me go through and it made me angry. So I feel was extremely that’s discrimination, like I told name you got show more-the woman I talked with she was good- they helps everybody. They just show favoritism in certain parts of the food bank….Yeah, it does stress me out, sometimes forgetting to take my medicine and- I let my doctor- I be honest with my doctor and I don’t keep it from her. I let her know I messed up two or three days. (Participant 016, Interview 3)</em></td>
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<tr>
<td><strong>Race/Class</strong></td>
<td><strong>Participant confirmed that she had experienced racism and was asked to give an example</strong></td>
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<td><em>Um, I think um a long time ago- remember I told you the story about my grandmother? A white man he was- he had to be like eighty-something he called us n----- just because we were Black. Yeah, that was in [name of town], cause [name of town] is you know mostly white people. Oh my gosh I can’t-yeah…Okay, yeah, mostly White people in [name of town] so people look at you like that. Even sometimes your own- my own color look at you like that.___________ or above cause you not making the money that they making…You’re always being judged. (Participant 016, Interview 3)</em></td>
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<tr>
<td><strong>Race/Class</strong></td>
<td><strong>Participant asked to describe how being African American impacts her ability to take care of her HIV</strong></td>
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<td><em>Mm…insurance, getting coverage…In my, yeah because that’s just my experience in that area. Like if for example, I’ve been fighting for Medicaid since oh nine. And I just received it two week, a week ago-two weeks ago, from oh nine so I just feel yeah…if you don’t know where like if you don’t know where to-you might not have coverage, you might not have um, transportation but you don’t know that the, health department offers free or low, low um reduced whatever you never go there for that. So it’s just…kind of linger around whatever until they end up in the ER by accident or….dead. (Participant 1, Interview 3)</em></td>
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Race/Class/HIV-related Stigma
Participant asked to describe in what ways, if any, her class/financial resources impact her ability to care for her HIV

Um, I think it impacts it a great deal.... And I don’t feel like there are enough resources out here, I think we rely too much on the old thing, the thing that’s been around. ... I appreciate [organization] and [other organization] they are doing some wonderful things. Great things and they’ve come a long way and they’ve helped a lot of people so I don’t undermine that. But at the same time you also always have to do an internal check to make sure that the people you’re providing services for are really satisfied and that they’re getting their needs met. And that they’re not being mistreated because why do I need to come here to be mistreated? So I went there, I needed some work on-I went to [organization], I needed some work on my mouth and I was so devastated that the guy that helped me, he doesn’t even work there anymore ... Everybody else gave me so many problems and so much drama, it was just always like a spirit of dread. And I mean I just made a vow to myself I said ‘look I just got to make sure that I keep it together because I can’t go to these people for resources’ like I can’t, I mean I don’t even go for the food bank and I would do that because I don’t get food stamps, I just try to maintain. It just pushed me harder to maintain because I can’t be caught up in that. I can’t be caught-I’m not going to come up in a place and be made to feel inferior, I’m not you know, or feel ashamed, and that’s not why you’re here. You’re not there for that. I just, I don’t understand. And nobody says anything I guess because they have, they’ve been doing it for so long and I guess they feel like it’s right but it’s wrong, wrong in so many ways. I just feel like its just time out, you know, and they service the black community so like who is really going to question them? Who is really going to go in and be like ‘are you really treating your people right do they feel like their privacy is protected here?’ (Participant 4, Interview)
**Motherhood/Gender/HIV-related Stigma**

Participant asked to describe being a woman living with HIV

Um, well it's scary because like when I got pregnant with my son I didn't want to have him because I didn't want to give him HIV. And then when they told me they can give me a different kind of medicine- that he won't get it- it was still you know I guess a 50/50 chance that he could have got it. Then I was supposed to have a C-section and I had him vaginally so he could have got it. But he didn't have it. Then I got pregnant again and I said I didn't want to bring a baby in the world like that. Then when they get older then they'll get mad at me. The other thing they'll do is get mad at me, "Mom, why you do this to me? Put my life at risk?" And stuff like that. So all that was coming into play in my head when I thought about it. Cause when I got pregnant with her I said- I didn't want her. I didn't want him either, when I was pregnant. And then I said I didn't think anybody would want to be with me with the HIV plus I'm having a baby and I have HIV. Cause I know a few people, they didn't want to be- they didn't want to be bothered with him cause they thought that he had it. I'm like, it's just so dumb so- a lot of people is really dumb to the fact. (Participant 013, Interview 3)

**Gender/HIV-related Stigma**

Participant asked to describe her experience of being a woman living with HIV

Well it's very hard due to um, I think people stare at me and um, when I go to the doctor um, well I've learned a lot about it by me living with it and being a woman. Um, when I go to my primary doctor at the Health Department um, there are different things that goes on with a woman. A woman body-it carries longer than a man. (Participant 017, Interview 3)

**Gender/HIV-related Stigma**

Participant asked if she had ever been stigmatized as a mother living with HIV

... Like I was saying earlier, um, a lot of people they find out first thing come to their mind like you've been with a lot of men or what was you doing, or you've been doing drugs. It's got to do with you're selling your body or doing drugs. Why couldn't I had a blood transfusion, or I was raped, something that I had no control of...Or...or my husband or my mate for years he gave it to me, he cut out. I mean why couldn't it have been something of that-it's always, like the first impression or first thing is like you've been with a lot of men or you did drugs, or you do drugs, it's never nothing like 'it wasn't my fault' it was always like 'yeah it was your fault.' And I just, I just, that's sort of overwhelming with me and it's still like that. (Participant 2, Interview 3)
### Gender/Race/HIV-related Stigma

**Participant** asked in what ways, if any, she felt being a woman impacted her experience of living with HIV.

I don’t know, it’s like a lot of people…for a black woman, to me, they find out you’re HIV or AIDS, you’ve got to be, you’ve got to have been a prostitute. Or you had to sell your body or you’re considered a little bit like nasty. Yes…a couple of years ago I was in a class, I mean, when I was first diagnosed I did a lot of classes and a lot of studies and things of this nature and…and um I was in a class after the class and a lady no a man, my fault, a man had the nerve to ask me he said ‘did you sleep with a lot of people?’ and I was like….no. And it sort of threw me for a loop and um…I was like ‘no why would you say that’ and he was like ‘well most black women with HIV I consider they’d slept with a lot of men’ as in you know prostituting or selling their body or stuff. I was like ‘no not in this case.’ you know, and it took me for a loop you know…That’s why you know like I said, my last interview before that was like you just can’t let everybody know, it’s not tha I’m ashamed of this but there’s a lot of cruelty out there you know? (Participant 2, Interview 3)

### Gender/Race/HIV-related Stigma

**Participant** confirmed she felt stigmatized and was asked to describe an experience of being stigmatized.

When I was because I am from in [another state], so when I was up in [other state] and I had to first um…go to a clinic and the first clinic I went to um…I don’t know it just, the people there made me feel like…you know, ‘uh’ you know that they didn’t want to be bothered with me, that she’s just another black girl coming in here with this disease. They didn’t know how I contracted it, they didn’t know how, just you know it could have been through a blood transfusion it could have been anything you know that they didn’t care it’s just that ‘she got HIV’ you know. Act like they didn’t, they were so cold you know? And I had left the clinic, I mean I left crying and in tears and it took me some time to find a level that I was comfortable with. (Participant 3, Interview 3)
| Gender/Race/HIV-related Stigma | ... just the fact that so many African American women are dying from this disease you would think that it would be talked about more in our community. But instead, they don’t. You can go to so many different churches on a Sunday morning on a Wednesday night, my church for example, my old church and he thought he was, and he was an educated man, married to a dentist, not once did he ever mention HIV in the eight years I was there not once did he ever discuss it across his pulpit, never...ever, ever. Community depends on church, they get a lot of their information from church. Even going back to the Civil Rights movement it started with the church and that’s how, that was their meeting place. So in order for an affective change to come in this community as it relates to this disease it’s going to have to be birthed out of the church. But they don’t want to, that’s not everybody, some churches do, they’ll talk about it, embrace it, teach on it. Others shun it, so you know, but once it started, I think the movement comes in the church, then we’ll see a change. But it has to come, that’s where because people want to be accepted. We want to be accepted, we want to be you know, and if we can get the leaders in the black community in the churches to start talking about it across the pulpit and say this is serious, and then it’ll cause-and educate people, then we can see a change. But yeah right now, yeah they don’t, they don’t. I talk to other people like ‘oh ya’ll have a’ you know what’s going on just to kind of talk in hear-nothing. Nothing’s happening, nothing’s yeah, it’s not talked about. So I mean I think you know that will be a powerful move...that’s where they get their information, the news and church and their peers. [laughs]
(Participant 4, Interview 1) |
<p>| Mutually Constituted Vulnerability |
| Gender/HIV-related Stigma/Motherhood | I'm not sure how different because I don't know precisely what men go through but I know just in general, um, I feel like when society sees a woman who is HIV positive, she's viewed differently than a man. I've always felt that way. Yeah. I feel like it would be, um, I have an idea and I could be wrong. I think somebody said 'no you're wrong and I think' but basically I felt like it would be easier for a man with HIV to find a mate versus a woman to find a mate. I don't feel like men are as understanding in that area as women. Someone said I was wrong but I don't know, I'm waiting to be proven differently so we'll see. The jury is still out on that. But um, I think for me, um, having children you know? ... I know that when I um, when I got pregnant with my daughter, I faced a lot of ridicule. (Participant 4, Interview 3) | Mutually Constituted Vulnerability |
| Gender/HIV-related Stigma/Motherhood | Oh yeah, so yeah I think that was it. And just having that I was speaking in reference to the doctor and the nurse and being pregnant and them telling me that. So I remember that to this day you know, and my daughter is fine, and my son is fine. So you know, so yeah I think it was a difference there telling me that. So I remember that to this day you know, and my daughter is fine, and my son is fine. So you know, so yeah I think it was a difference there because she wouldn't have been having a conversation with a man about that 'cause he [a man] wouldn't be giving birth so yeah. (Participant 4, Interview 3) | Mutually Constituted Vulnerability |
| Motherhood/Gender | Taking care of kids, having kids, having children running around and working. ‘Cause I know for me, for years I like I got to work, I got to work and put my doctor’s appointments to the sides because I had to go. And I rescheduled, I rescheduled, I rescheduled. And then it becomes a, after you're done reschedules it's like yeah forget about it—I'm feeling fine... (Participant 1, Interview 3) | Mutually Constituted Vulnerability |
| Gender/Class/Race/Motherhood | Cause I feel like being Black it's hard already, that's already one strike and I'm a woman, that's a second. So that’s a lot it's like you got to fight your way all the way through... Yeah, you have to fight to keep your place. You got to keep your car. You have to you know work and you have to do everything you can just to keep everything. Sometimes you got to take jobs you don’t want to do. (P laughs) But you got to do it to pay the bills. (Participant 016, Interview 3) | Mutually Constituted Vulnerability |</p>
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<tr>
<th>Motherhood/HIV-related Stigma</th>
<th>I don’t want them to be embarrassed.</th>
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<td>Participant asked why she had decided not to disclose her HIV status to her children</td>
<td>Well like if I try to meet a guy or like I go on a date or something and she be like “mmm.” I say ‘well we’re not going to have sex or whatever’ she’s like ‘well I don’t think you should tell him, don’t tell him right away, because he might run away’ or she like tells me, like umm... how does she say it? She says ‘Mom, she says sometimes I just want you to keep it a secret because you know people judge you. She always says he seems like he’s nice, don’t tell him right away.” I was like but ‘Well eventually I’m going to have to tell one of them’ and she’s like ‘Well you can keep it a secret as long as you don’t have sex.” I said but ‘Well, yeah but then it will be on my conscience.” You know like situations like that. (Participant 010, Interview 1)</td>
<td>Mutually Constituted Vulnerability</td>
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<td>Motherhood/HIV-related Stigma</td>
<td>Um...well I- I think they treat me pretty good. You know sometimes I know I have to be careful about things I do- like if I get cut or something like that you know? I have to take you know precautions and stuff or I wouldn’t want to be bothered with them until I get all this stuff cleaned up. But I don’t think I have been treated different. I know a lot of people- when I got pregnant they were shocked like &quot;How do you get to have a baby and have HIV?”...Like when I was pregnant with him, &quot;How did you get pregnant?&quot; Mm-hmm and then when I got pregnant with her, it was shocked again. Like, &quot;How do you get to have a baby and you have HIV?” I said, &quot;I'm just like any other person. The only thing different is I have HIV.” So that- that was- people still in shock, especially cause they haven't seen my daughter yet- anyway and they still in shock like, “She's pregnant?”... A lot people didn't know they were like, 'How do you get to have a baby and have AIDS?’ I'm like, ‘Are you serious?’ So it's very interesting. (Participant 013, Interview 3)</td>
<td>Mutually Constituted Vulnerability</td>
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Race/HIV-related Stigma
Participant described living with HIV in the African American community.

Just the way we [the AA community] approach the disease is just... it's mind boggling to me... I don't think that, just listening to the things that I hear I can't really say about you know what kind of conversations are being held in other communities. But I know in my community, we're still far behind in our thinking. And it's sad, because um the conversation you know I'm around so many people and so many people don't know my status. I'm around professional people, I'm around just everyday students, just different people.

Homosexuals, lesbians, you know I like to talk to people, I like to mingle, I just like to hear what people are saying and so some of the conversations that they're having it's just amazing to me. Um... the ignorance that's still out there with all the knowledge that's out there the ignorance is just overwhelming. And I'm thinking to myself, there is so much information that's available to you, and you just have to pick it up, you have to. it's a choice. To me ignorance is a choice, it is, it's just a choice. It's a choice you make. Especially when you want, when the information is out there, you know if you want something bad enough you have to go get it you have to be willing to seek it out and find it and know that you know, this is, I need to know... but for some people they just rely on what other people are saying. And go with that.

(Participant 004, Interview 1)

Mutually Constituted Vulnerability
**Race/HIV-related Stigma**  
Participant described a photograph she had taken that represented the HIV-related stigma she experiences

| So if their preachers aren’t talking about this disease, that’s killing so many black women and just killing people in general, they’re not discussing it and they have a phobia, and they’re afraid to talk about it and you know, and won’t address it, then I don’t think the community will ever, the black community will ever grow and get past this and truly understand the devastation and the disease you know and what comes with it. I think they’re still very ignorant behind this. Like I hear crazy stories, stupid stories, like how can you still be about HIV and you know how you contract a disease, how it’s transmitted, how-well ‘I don’t want that person in my house’ just that, I’m like really? It’s like the dark ages. I’m just like-and it’s amazing to me because a lot of people don’t know that I’m positive but they’ll say things around me and I’m like ‘that is just the dumbest thing I’ve ever heard.’ And I feel like a lot of it if the war was truly, if we want to win the war if we want to get people to really understand this disease, because it is such a, it has such a negative, such negative publicity behind it and you know, when everybody was you know, and how many ways you can get it and this, that and the third. And now it’s so focused on you know, ‘oh man’ you know ‘I don’t want to catch this, I don’t want to catch this’ and they’re focused on so much negativity behind it. But people are getting sick and they’re dying and we need to think about how can we save people? So and how can you make them feel better, and how can you help them cope? (Participant 4, Interview 2) |

<p>| Mutually Constituted Vulnerability |</p>
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<th>~Motherhood/ HIV-related Stigma</th>
<th>Participant asked to describe being a mother living with HIV</th>
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<td>It just means well truthfully to tell you this I have not told my kids as yet. I just don’t know how to come about saying it because I have a 22 year old and I have a 15 year old. Now the 22 year old he was this was of making jokes about stuff like that, so in a way it makes me feel ashamed to turn around and say well guess what when you make those jokes and I get mad at you this is the reason why, is because I have that illness that you’ll make jokes about. You know like we’ll be walking down the street and he’ll see someone that might gaunt or whatever might not even have anything to do with that. I worked in the health field myself so I know its look at me. I look healthy, but I mean it hurts but he just has this thing of oh look that person looks like or it might be someone he knows and he figures okay they lost a lot of weight and the first thing he blurts out is they must got ‘that thing.’ That’s what they call it, ‘that thing’ or ‘that monster’ and that really just pushes me more to not be like well listen kids sit down this is what’s going on with mommy. Um, they have seen me taking medicine because I take my medication every night. They don’t see me do it every night ‘cause now I try to hide and do it so um they wondered for a while why I was taking medicine.I told them it was for depression. And just left it alone. You know I mean I was depressed anyway. So I use that as the excuse and um I just basically left it like that. I haven’t actually told anyone, even my mom and we’re like this and I know that’s going to hurt her because the first thing she’s going to think is ‘oh she’s dying’ and I don’t know how to describe to people I’m not dying I’m living. I don’t know about ya’ll. I might out live some of ya’ll, but everyone has that stigma of HIV even myself included in the beginning cause I’ve had patients that were HIV positive and I was with them for years. So I know people can go on. There’s just some people who they either were never diagnosed or were not diagnosed in time so they couldn’t get the viral load up. Thank God I did what I had to do. Well maybe I should say the pregnancy. And I was on it like [snaps] and um but basically that’s it for me.</td>
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<td>(Participant 11, Interview 1)</td>
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### ~Motherhood/ HIV-related Stigma

**Participant** asked to describe a photograph she took

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<th>I: what do you see here?</th>
<th>P: The front door.</th>
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<td>I: ... how does that relate to your health?</td>
<td>P: Well I have to leave through my front door to go to my appointments and um, doctors- well doctor’s appointments about my health and sometimes it can be stressful, overwhelming. And just people outside of that door that you know that are just mean and negative. I don’t think everyone is understanding.</td>
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<td>I: So how does that relate to your health do you think?</td>
<td>P: Well like I said I have to leave through the front door to- to go and not all the time do I want to. I see, mm-hmm. So do you consider that a strength or a concern? P: Mm, it’s not- it’s not a strength but- but it’s not a concern either. Because regardless, I have to maintain my health for my children and I ignore the negative. <em>(Participant 18, Interview 2)</em></td>
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### ~Motherhood/ HIV-related stigma

**Participant** confirmed that she had experienced stigma as a mother living with HIV and was asked to describe such an experience and if impacted her accessing care

| Um, from family, siblings, and my biological mother and you know just telling people when they’re mad at me that, “Oh, you know she’s positive. That’s why she’s gonna die” saying you know stuff like that...Well we all know Facebook is a way of communicating over the internet and I have had family post that I was positive up there you know for the whole world to see. Because they were being mean and spiteful but just- it’s not really nothing to be secretive about. But like I said once before there are people that are ignorant and excuse my terms but they’re just ignorant and they lack knowledge and understanding of the whole meaning of being positive with HIV or you know how you can come in contact with it. What are your chances and risks? You know they are just ignorant to the facts and to show people that I am is- is just hurtful because then I have those people that bypass me and my you know screwface me or might tell their friends and then their friends tell their friends and it’s just a whole big cycle of hurt. *(P laughs)* ...[impact her accessing care?] Um, no not really. Um, my motivation is my children and my family. I don’t see how that- that anybody in my situation could ever say you know someone’s talking about them- you know that might make them hurt even worse or I guess lead to other things. But you gotta have a strong motivation and a will. *(Participant 18, Interview 3)* | Opposing Determinants |

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Participant asked to describe being a mother living with HIV

Oh yeah definitely I think that’s-as matter of fact I know that’s why [her children] I’ve made it this far, because I don’t think if it was for them, I probably would have given up a long time ago. I have those days I’m just like I don’t want to do this I’m tired. But I have to remember my children so you know...that to me is a blessing and I look at it as if God knew, he knew that I would need that kind of motivation because if I did not have my children I’d probably just lay down in a corner somewhere just like leave me alone, let me die. I mean just because I think it is the medicine, society, you know some people will say ‘oh you’re not limited in what you can do if you’re HIV positive.’ There are always going to be limitations until the thinking, until the mind change, until um...until there’s an actual change in humanity and our mindsets it’s going to always be an issue and a problem...you know. And unless you move to you know you just have this utopiawhere everybody loves everybody and everybody gets along, no one sees color no one sees anything they don’t see you know shortcomings and you know, and we’re not there, so...there’s you know what you I think that’s just...part of life and you know, and we deal but I think it’s just so much harder especially not in my community. (Participant 4, Interview 1)
Participant described how her experience with HIV-related stigma helped in explaining and teaching her niece about disability stigma.

So each time I try to explain it, to her it seems like it's getting harder and harder for me to explain it. Cause the little kids next door they tells her things like- I don't know- they teases her about it. She gets mad but I tell her, "Don't- don't listen to that. You don't have to worry about that. Cause them not good kids if they gonna tease you about your aunt's leg and all that. Those are not kids you need to be around, no way." So she don't play with 'em anymore. She even told 'em, she said, "I shouldn't have to play with y'all if y'all gonna pick at people cause you shouldn't pick at people. They taught me that at Sunday school." And I'm like, "You don't do that to other people because if something is wrong with you-you don't want them to do it to you." So I think she remembers that each time somebody wants to say something to her bad or something. She just turns the other check and walk away. So I pretty much taught her that part though, because I got the anger behind it myself and when people were saying that I had HIV- "Oh, well we know that you got this." Or, "I heard this." Okay I got to the notion that I would tell 'em, Okay "You said I got it. When did you become a doctor? And then you need to have yourself checked before you go to say someone else have something. Go and have yourself checked," And then I thought, 'Well I'll just learn to ignore it.' Because I don't feel like I got it. I don't look like I got it. Actually every morning I get up I feel good. I really do, I don't feel sick, feel like I need to be on drugs behind it, or get a drink cause I'm feeling bad behind getting it. Don't know how to explain things to nobody else. I think the more I educated myself about it the more better I got about it or I feel about it. So that's a good thing. She- my niece ain't- she don't, they ain't taught them that in first grade yet, so I can't explain it to her yet. But I figure when she get in like the 6th they gonna have more or they gonna have a cure for it. So that way that'll be some part of my life that'll be in the past, then I may explain to her about it in case it come back up and don't nobody been there. (Participant 17, Interview 1)
<table>
<thead>
<tr>
<th>Motherhood/Race/Class/Gender/HIV-related stigma</th>
<th>Participant asked to describe how being African American impacts her experience of living with HIV</th>
<th>Opposing Determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think just dealing with the ignorance and the stigma in the African American community I think it hinders me. Every time I go to the clinic I'm like 'oh God… I hate walking this wall, people so nosey in this hospital'... And then even with [different organization] I'm like, these places are here to help people but for me I've had bad experiences there... I just feel like we categorize people sometimes, especially, especially African American women are often categorized. Like at the end of the day if you want to take care of yourself and you want to look like something then they feel like 'oh yeah you've got this, you've got' no! No I don't have! No my bank account says zero it's just I refuse to look like I'm tore down and broke down like why do I have to look like that! Who says I have to look like that? I don't have to look like that. I choose not to look like that. And I choose for my children not to look like that. They don't have to look like we just came out of a dirt, a hut or something, what! No, mm-mm, no. I just think I'm not going to go any place just looking broke down for you to help me. This is who I am, either you're going to help me based off the fact that I need the help, and I meet the criteria or you're going to make it hard for me. (Participant 4, Interview 3)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix J. Participant 001 (Donna) Vector and Frame Analyses

When I met Participant 001, she was 39 years old and living in a homeless shelter for families in an urban area of the Research Triangle of North Carolina. I will call her Donna. Donna was married and living in the shelter with her husband and two teenage children. Donna also has three adult children living independently outside the home and two grandchildren. All three of Donna’s interviews took place in a common room at the shelter. At the time of the first interview, Donna was 3 weeks post-op from a major hip surgery and was using a walker for ambulation. Donna held a CNA license and was previously employed as a nursing assistant. Secondary to a hip injury she incurred at work and subsequent surgery, however, she was unemployed. She emphatically stated that she has “no income” but that the homeless shelter is a “help.” Donna has been living with HIV for over 23 years and described herself as a “real private” person.

I chose to name this case “A Hard Case” because Donna’s first response to a question about what it was like to be a mother living with HIV, she responded that it was “hard.” She then went on to repeat the word “hard” several times during her interviews referring to various aspects of her life.

When reflecting on her life as a mother living with HIV, Donna reported that it was difficult to balance the demands of the children’s school sports/activities and the other stressors in her life. She said that the children’s activities are positive for the
children, but used words like “hard,” “challenging” and “crazy” when describing the impact the activities had on her life. She also described missing health appointments “like crazy” in the past as she tried to balance work, family and her health. Donna stated that the aspect of mothering that she found most pleasurable was watching her children grow. The aspect that she identified as most difficult was her children being unaware of her HIV status. Donna has disclosed her HIV status to her husband, but not to her children. During the informed consent process, Donna did not grant permission for the photographs of her and her children to be used for research presentations or publications.

Disclosure of her HIV status was a major storyline in Donna’s interviews. She described several strategies she developed to keep her HIV status secret, including tearing the labels off her medications, hiding the medicine bottles and burning the containers once they were used. Donna described several negative consequences from an experience in which her husband disclosed her status to his family members. Donna reported that she felt his disclosure of her HIV status has “drastically” changed her relationship with his family and that it created a “whole monster of attitudes” (Interview 1). Donna also described being estranged from her own mother when she disclosed her status to her mother. Donna expressed concerns about the unintentional disclosures to acquaintances and being seen going into the infectious disease clinic at the hospital.
Donna reported being “leery” of disclosing her HIV status to her children. She states “I don’t….I don’t know! I don’t, I don’t know….” (Interview 1) She cited a potential positive aspect of disclosing to her children in that they may be able to help her. She expressed concern, however, that they may worry too much if she becomes sick and think that she may die. Ultimately, she concluded, “I don’t want them to know” (Interview 1).

Donna placed value on educating her children about HIV and other sexually transmitted diseases. So much so, she reported attempting to shock them into compliance. For example, she intentionally posted in her home “gruesome” or “the nastiest pictures I could find” of genital sores in order to educate her children about sexually transmitted diseases (Interview 1).

Another major storyline in Donna’s interviews was her perception of healthcare providers and the healthcare system. Generally, Donna did not portray a positive perception of healthcare providers. She relayed experiences in which physicians and physician assistants had an “attitude,” treated her like she was “taboo,” didn’t seem to want to touch her and suggested that she had a death wish (Interview 1). She relayed stories about nurses being “rude,” misinformed about HIV and incompetent. She described that her experiences have, at times, kept her from returning to a particular provider or prevented her from seeking medical care all together. Donna suggested that, almost as compensation, she pays special attention to HIV-infected patients and “caters”
to them in her own work as a nursing assistant (Interview 1). She also described differences in the healthcare systems in the Northern region of the country (where she used to live) and the South. She suggested that in the North, the system does a poor job of maintaining HIV-infected people’s privacy/confidentiality and her statement seemed to be based on an experience in which her confidentiality was breeched in a health setting. She did perceive that the health services were more accessible in the North, however. She suggested that in the South, it is much more difficult access services and that she has been “fighting” for services and health coverage (Interview 1). Donna described that the difficulty access services and health coverage in the South has caused her to delay essential dental care. She was also concerned that she may not be able to maintain her HIV “medicine flow” as needed and stated that health care access is “life or death” (Interview 1)

Donna reported she felt there was a general ignorance about HIV in the community. She described feeling a great deal of anger when others made ignorant statements about HIV and stated that such statements really “piss her off” and “bother her to the fullest” (Interview 1).

Donna reported one pivotal health experience that altered her course in health maintenance. In 2009, she became very ill and was hospitalized on two occasions for what she described as a “hole” in her esophagus. Her CD4 cell count was very low at that point as well. She described that her husband and co-workers were very concerned
and supportive. She recovered slowly, but since that time she has more regularly
maintained her medications and health appointments. Her viral load has been
undetectable since that time.

Unfortunately, the photo elicitation interview with Donna was relatively short,
because she did not take very many usable pictures (her children got the camera and
took several pictures of themselves). The interview was interrupted several times by her
husband and they were having a difficult time because he had recently been ejected
from the shelter for substance abuse. Despite these barriers, Donna thoughtfully
considered each picture as we went through them and responded to each of my
questions. Overall, Donna focused more on negative social health determinants and only
identified her medicine and her car as positive health determinants. Her surgery
recovery (comorbidity) was also a theme in her interviews.

Table 12: Conceptual Model Social Determinants for Donna

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
</table>
| **Motherhood** *(M)/Gender (G)*  
Asked in what ways, if any, being a women impacted her ability to care for her HIV | *Taking care of kids, having kids, having children running around and working… ‘Cause I know for me, for years I like I got to work, I got to work and put my doctor’s appointments to the sides because I had to go. And I rescheduled, I rescheduled, I rescheduled.* (Interview 3) |
| **Race (R)**  
Asked in what ways, if any, being African American impacts her ability to care for her HIV | *Mm…insurance, getting coverage….In my, yeah because that’s just my experience in that area* (Interview 3) |
| **Class (C)** | *Mm…I say finances…Because if you can pay to go somewhere* |
| Asked to identify most detrimental social determinant of health | "differ or go further out where like nobody will come, (laughs) even if it’s the same place if I have Medicaid but there’s a clinic in [different town] because I don’t have no funds to get to [different town] then I’ll have to settle for local so yeah. (Interview 3)"

| HIV-related stigma (S) | "It would be like little simple stuff. If, if I remember I one, she was a PA, and it was just like she had an attitude. It’s almost like…like she didn’t want to touch when she was doing the, when she was talking there wasn’t no blood exchange—because I’m a CNA—there was no blood exchange or no risk of her getting anything. So it was, and the way she…just the way she acted was just like she felt like it’s a taboo So, I didn’t go back to that clinic, I didn’t go back. (Interview 1)"

| Self-assessment of health (+) | "Mm…well, I’m working on my health. (laughs) I think generally I’m pretty healthy. So I would say…not being sickly and…have all of this opportunistic infection and stuff in that aspect I’m pretty healthy… I could be healthier but I think I’m generally pretty healthy (Interview 3)"

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**Figure 51: Vector Model for Donna**
Table 13: Donna’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>001 Internalized Frame</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIGH</td>
<td></td>
<td></td>
<td></td>
<td>I just have a have a taboo, about going to the clinics and stuff... and confidentiality that’s a big thing for me. And the way people still treat. Because if you’re listening to people and they talk not knowing who is or who isn’t, its just like you’re rude you don’t even know…you don’t even know anything… (Interview 1)</td>
</tr>
<tr>
<td>LOW</td>
<td>Because I have teenagers and then they’re into sports in school so it’s like trying to keep up with school activities, and then after school activities and then trying to make sure you don’t miss your appointments and what not, is, sometimes it gets crazy…Actually at first I, when I first started, when I first started going to the doctor down here I would miss appointments like crazy. (Interview 1)</td>
<td>...they [her children] don’t know…I mean they see me take medicine but they don’t know what it’s for so I have to keep that like a secret from them…but and then if I get sick they don’t really know. (reports the children not knowing is the hardest part of caring for them and that she hides her meds and burns the labels) (Interview 1)</td>
<td></td>
<td>None noted</td>
</tr>
</tbody>
</table>
Appendix K. Participant 002 (Fran) Vector and Frame Analyses

When I met Participant 002, she was 42 years old and living in an urban area of the Research Triangle of North Carolina. I will call her Fran. All three of Fran’s interviews took place in a private room at the university. Fran was married and has one teenage daughter. Based on the reported timing of her HIV diagnosis, Fran was diagnosed with HIV when she was pregnant with her daughter. At the time of the interview, she was employed as a home health nursing assistant and worked primarily with the elderly. During the informed consent process, Fran did not consent to having the pictures of herself and her child used in research publications or presentations.

I chose to name this case “A Case of ‘I was something!’” because Fran relayed the story of her behavior when she was first diagnosed with HIV and described being feeling angry, mad, fearful of death, “not a happy camper,” like a “disobedient child” and having a “bad attitude” (Interview 1). As she relayed the story, Fran repeatedly and emphatically said “I was something!” (Interview 1)

When reflecting on her life as a mother living with HIV, Fran told the story of a slow progression toward health. Fran described the early years of her diagnosis as “rough” and “hard” and she repeated these describing words many times as she recalled that time period (Interview 1). She said it was particularly hard when her daughter was an infant and toddler. Her daughter’s father was not involved and at the
time she had little social support. Fran reported feeling very fatigued, low on energy and ill during those years. It seemed her physical health was compounded by her emotional response to the diagnosis (i.e. “I was something!”). In a nonlinear fashion, Fran described several things that moved her toward health and acceptance of her diagnosis. First, she reported that she decided to educate herself about her disease. Second, she reported turning to the Bible and God. Third, her daughter grew older and eventually went to school, which created what Fran described as “me” time (Interview 1). She reported having more time to concentrate on herself and health. Fourth, Fran’s sister began helping with her daughter in the afternoons after school. Finally, Fran described a move her physician served as a pivotal moment in her health self-maintenance. Her doctor called her out for not taking her meds, missing appointments and not maintaining her health. She reported that he said something to the effect of “I’m just going to stop seeing you because you don’t want to live, you don’t want to get well. So, this will be our last time seeing each other...I don’t want to see you anymore because I’ve got other patients that are really trying to get themselves together....it’s a waste of my time” (Interview 1). She described it as an epiphany and she realized that she too wanted to live. Since the early days, Fran described her life as a mother living with HIV as “smooth sailing,” much easier and “ordinary” (Interview 1). After each of the changes above, she was able to start working again, she gained weight and her viral load became undetectable. Fran reported the most difficult aspect of mothering with HIV was the
fatigue and low energy when her daughter was young. Fran reported that the aspects of mothering that she finds most pleasurable are seeing her daughter happy and teaching her things such as cooking and personal hygiene. Fran also acknowledged that she can’t teach her daughter everything and that if she doesn’t know something they will find out the answer together.

Fran’s relationship with her daughter was a major storyline in the interview. She described working very hard on their relationship and said it “ain’t easy” but she describes it positively and said they have very open communication (Interview 1). Fran reported that she desires her daughter to come to her with her needs, so she very intentionally does not show anger or frustration. Fran had disclosed her HIV status to her child.

Fran’s relationship with her physician was also a major storyline in the interview. Fran reported having the same physician since she was diagnosed with HIV. She expressed a great deal of affection for him and called him her “buddy” and “bud” (Interview 1). She appreciated his honesty and said that he doesn’t “sugar coat” things (Interview 1). She also reported that he is willing to spend time with her and answer her questions. Fran lamented the day he will retire. She reported that he also has helped her with her general health maintenance, losing weight and controlling her asthma.

Over the course of time, Fran reported relinquishing certain things like blame and complaining that she believes won’t help her situation. She reported relying on God
and the Bible and feeling very blessed. She repeated feeling blessed multiple times throughout the interview and stated twice that when she dies it won’t be from HIV, it will be from something else.

Fran’s photographs focused exclusively on positive health determinants and many of them are focused on the social supports (human and animal companions). As a result, several of her photographs were not usable because she did not consent to sharing the photos of herself/her daughter and the photos of the other support people in her life were not usable per the study protocol.

**Table 14: Conceptual Model Social Determinants for Fran**

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motherhood (-M)</strong></td>
<td>We [she and her daughter] have that understanding come to me with anything! I will never get upset, even if I am upset inside I won’t let her know it, because I always want her to come to me first… Talk to me, even if you’ve done something! You know we will get through this together. (Interview 1)</td>
</tr>
<tr>
<td><strong>Gender (G)/Race (R)</strong></td>
<td>Um…hm…um…I don’t know, it’s like a lot of people…for a black woman, to me, they find out you’re HIV or AIDS, you’ve got to be, you’ve got to have been a prostitute. Or you had to sell your body or you’re considered a little bit like nasty. Yes. (Interview 3)</td>
</tr>
<tr>
<td><strong>HIV-related stigma (S)</strong></td>
<td>And I just, I just, that’s sort of overwhelming with me and it’s still like that….And I’m like ‘why do you always think the negative things’ like ‘what did you do’ what if somebody did something to me you know? (Interview 3)</td>
</tr>
<tr>
<td><strong>Class (C)</strong></td>
<td>Um…I think a lot of resource is limited and it’s well I’m talking financial side of….it’s just limited and it’s just…it’s not enough….I mean the Medicaid and things of that nature…Um…every year they are limited more and more. (Interview 3)</td>
</tr>
<tr>
<td><strong>Self-assessment of</strong></td>
<td>Having your right mind, you’re in your right state of mind…that you</td>
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</table>
Reported that she was healthy based on her definition of health.

know right from wrong, your right state of mind. You know how to feed yourself you know, common everyday things you can do for yourself. I think that’s healthy I really do. Because I know working in the health field a lot of people are not blessed, or not necessarily was born that way. Their mind, I think when your mind is sort of not together, you’re not healthy. (Interview 3)
<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>002 Situational Frame</td>
<td></td>
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<tr>
<td><strong>HIGH</strong></td>
<td>That’s my daughter...That’s a strength of mine. I’m like ‘whoa’ lots of times in my past, every now and then I will still be like I just want to give up—not necessarily give up like kill myself, nothing like that; just like say just tired of this… Then I’ve got to think about ‘what would she do’ you know? What would she think ‘mom just left me?’ You know, so that’s a motivator for me to just stay put, take a couple of breathers, take a little time out, think about it in…you know...</td>
<td>But I feel I need to be around as long as I can so she can at least know me. So I can show her and teach her what I do know, you know, and we can learn some things together you know? (Interview 2)</td>
<td>…you just can’t let everybody know, it’s not that I’m ashamed of this but there’s a lot of cruelty out there you know? (Interview 3)</td>
<td></td>
</tr>
<tr>
<td><strong>LOW</strong></td>
<td></td>
<td></td>
<td></td>
<td>I had to realize you know, I can’t blame anybody…I mean I can …but you know what good is that going to do? You know just, just be blessed and thankful that I found out...before it was too late...because I could have found out it was too late and my immune system was just gone or I had done got AIDS...And I’m just, I have to think about the Bible I’m blessed, girl please! You’re blessed, you did find out! I could still be having it now and not even know it and be about dead! You know I’m blessed so I have to look at the positive side of it, you know. It’s been fifteen years I’m like ‘what!’ So hey, I’m going to be doing fifteen more! (Interview 1)</td>
</tr>
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</table>
Appendix L. Participant 003 (Nora) Vector and Frame Analyses

When I met Participant 003, she was 44 years old and living in an apartment home in an urban area of the Research Triangle of North Carolina. I will call her Nora. All three of Nora’s interviews took place in her home. Nora was married and had six children. Three of the children currently lived in the home with her, but only one of them was officially still her dependent because she is under 18 years of age. Nora was diagnosed with HIV after her third child and at the time she was a prostitute and struggling with drug addiction. At the first interview, Nora reported being clean from drugs for 14 years. Nora had disclosed her HIV status to all her children and her husband and during the consent process she consented to having her photographs used in research publications and presentations.

I chose to call this case “HIV Made Me a Better Mom” because Nora articulated that her diagnosis with HIV has had a very positive influence in her life as a mother. Nora reported that when she was first diagnosed, she struggled with the diagnosis, felt “devastated,” was depressed and struggled to stay on her meds (Interview 1). During that time, Nora thought about dying frequently and had friends dying from AIDS. She reported that ultimately she made a decision that she did not want to die and began taking her medication. Nora described her journey as up-and-down and an “uphill battle,” but that she feels healthy now (Interview 1). Nora used her experiences to
counsel her children about protecting themselves and stated she sought to make every moment with her children count. She enjoyed participating in their lives and reported that having a close relationship with each of them was important to her.

Nora said the most difficult thing about being a mom living with HIV was that at some point she may not be there for her children. At times, Nora found managing her own health and supporting her children very tiring. Overall, however, Nora reported feeling fortunate and grateful to God for keeping her alive. She stated that HIV had made her both a better mother and a better person. Nora also described reframing her diagnosis with HIV by saying “why not me” instead of “why me” (Interview 1).

Nora’s photographs focused exclusively on positive health determinants and many of them focused on motherhood and her social support network. As a result, several of her photographs were of her children or representations of her husband who she identified as a major support. She also produced images of several other positive health determinants in her life such as: religion/spirituality, housing, transport and her health providers.

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
</table>
| **Motherhood (~M)/Gender (~G)**  
  Asked what ways, if any, being a woman                                           | Um…I don’t know if I can really answer that because…being a woman with HIV for me I would say it’s different because I’m a mother. So…I guess it impacts me as far as my children and the concern and stuff like that um, so I would say yeah it’s different for me you know, as far as the aspect of being a |
<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>impacted her ability to care for her HIV</td>
<td>&quot;...I guess my answer is just yes. [laughs] Being a mom it’s different. (Interview 3)&quot;</td>
</tr>
<tr>
<td>Race (R)</td>
<td>&quot;If color didn’t matter you mean um…no. I don’t think it would be the same. I don’t think it would be the same...I guess we would be treated a little better um…I don’t know, I just think if it was a color blind world that there would be no you know how some people kind of discriminate it would be that type of thing, so…it would be different. (Interview 3)&quot;</td>
</tr>
<tr>
<td>HIV-related stigma (S)</td>
<td>&quot;...because I guess they didn’t understand back then and they told their children when you go to auntie [name] house, don’t drink out the cups, don’t eat behind her, stuff like that. And it kind of hurt me and it hurt my children because they just didn’t want them period to come over. (Interview 3)&quot;</td>
</tr>
<tr>
<td>Class (C)</td>
<td>&quot;Um I would say…financially…um…that is the hardest I guess. Um…because I don’t have the, I’m on a monthly income so you know if I had money I guess I would be able to do more things you know that I need to do for myself. But um…that’s the one for me, I would say yeah. (Interview 3)&quot;</td>
</tr>
<tr>
<td>Self-assessment of health (+)</td>
<td>&quot;Health or being healthy. Um…health and being healthy is when you want to take care of yourself. You don’t miss your doctor appointments, you do what your doctor tells you to do. You take your medicine, you know, you try to eat healthy. Um…just taking care of yourself in general. You know, you want to be here then you’re going to do what you need to do to be here. (Interview 3)&quot;</td>
</tr>
</tbody>
</table>

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Figure 53: Vector Model for Nora
## Table 17: Nora’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIGH</strong></td>
<td>Being a mom it’s different. Because the man, he can go about his business you know and most of them are you know.... Um, makes it different because it makes you want to take care of yourself even more, you know, to be here for your children, to school them, about this disease. Um...’cause nowadays you know the young people are just running around sleeping with this one and that one and not really having concern about protecting themselves. So you know just being a mom and trying to be here for my children makes it better for me. (Interview 3)</td>
<td>...I think it [HIV] made me be a better mom....Because I just wanted like the relationship to be...like a strong bond you know. Like I said in the beginning I didn’t think I was going to live as long as I have. So I wanted every moment to count. And so our relationship, we’re very close, very close...and I think that has something to do with it. Not saying that if I didn’t have it you know I wouldn’t be close with my kids but I think it has impacted my life a little more you know? (Interview 1)</td>
<td>...I don’t know it just, the people there made me feel like...you know, ‘ah’you know that they didn’t want to be bothered with me, that she’s just another black girl coming in here with this disease. (Interview 3)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix M. Participant 004 (Eve) Vector and Frame Analyses

When I met Participant 004 she was 40 years old and living in an apartment home in an urban area of the Research Triangle of North Carolina. I will call her Eve. All three of Eve’s interviews took place in her home. Eve was divorced and her children, a daughter and son, lived with her. Eve was pursuing a master’s degree and worked part-time. Eve had been living with HIV for 19 years and reported that she had disclosed her HIV status to her children. During the consent process Eve consented to having her photographs used in research presentations and publications.

I chose to call this case “My children are why I have made it this far” because Eve articulated that if it were not for her children, she would not have had the desire to keep living after her HIV diagnosis. Eve talked at length about the importance of her relationship with her children and how she wished them to have the best in life. She suggested that having HIV has caused her to be a more protective mother, as she wished to protect her children from people that are ignorant about HIV. She reported openly discussing her diagnosis and the disease with her children. Eve stated that her relationship with her children is her greatest source of pleasure and that they have a lot of fun together. She stated, however, that it can be difficult to maintain a balance between all her children’s activities and her health. She described it as a constant challenge. She also stated that the most difficult part of caring for her children was not
having much support. Her ex-husband was not involved in their lives. She received 
some assistance from her cousin, but she was concerned about overloading him, so she 
purposely didn’t ask for much.

Eve talked a great deal about how having HIV has caused her to think differently 
about being a mother. She reported that she has tried to foster independence in her 
children from a very early age and wanted to prepare them for survival should she no 
longer be around. She stated that she wasn’t afraid of dying, she was afraid her children 
wouldn’t be okay without her.

Eve ended the interview with some insights about the African American 
community and its response to the HIV epidemic. She suggested that it is hard being 
HIV infected as an African American because the community does not approach it in a 
positive way. She said there is a fair amount of ignorance about the disease. In 
particular, she called out the African American church. Eve asserted that the African 
American church needed to play a much bigger role in fighting stigma and the spread of 
HIV. She reported that she considers the church a stronghold in the community that 
people rely on for information and guidance, therefore, it needed to take responsibility 
in combating the issues related to HIV.

Eve focused almost exclusively on negative health determinants in her 
photographs. She produced several very abstract representations of HIV-related stigma. 
Eve produced representations of how stigma and the disease have impacted her self-
perception negatively and how in turn that impacts her class, employment and produces fatigue. She also reported very little social support in dealing with these issues and was not complementary of the local support groups, expressing concerns regarding confidentiality. Eve also cited transportation as a negative social determinant of health. She owned her own car and reported that it is helpful in getting her children around and getting to her health appointments, but expressed that it was a financial burden and that the local public transportation was inadequate.

Eve represented some positives determinants of health in her photographs. She took a picture of the woods in her backyard and said that the dark woods represented her life, but that she can see the light and that is a strength. She did not specify what that light represented in her life. Finally, she identified entertainment such as movies and books as positive determinants.

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motherhood (~M)</strong></td>
<td>Positively I think just being a mom because my kids, like, if it wasn’t for my children I probably would not be still living. I probably be dead. (Interview 3)</td>
</tr>
<tr>
<td><strong>Gender (G)</strong> Reported being ridiculed for being pregnant with HIV</td>
<td>And just having that I was speaking in reference to the doctor and the nurse and being pregnant and them telling me that. So I remember that to this day you know, and my daughter is fine, and my son is fine. So you know, so yeah I think it was a difference there because she wouldn’t have been having a conversation with a man about that ‘cause he wouldn’t be giving birth so yeah. (Interview 3)</td>
</tr>
<tr>
<td><strong>Race (R)</strong></td>
<td>I can’t be caught-I’m not going to come up in a place and be made to feel inferior, I’m not you know, or feel ashamed, and that’s not why you’re here. You’re not there for that. I just, I don’t understand. And nobody says</td>
</tr>
</tbody>
</table>

Table 18: Conceptual Model Social Determinants for Eve
anything I guess because they have, they’ve been doing it for so long and I guess they feel like its right but it’s wrong, wrong in so many ways. I just feel like its just time out, you know, and they service the black community so like who is really going to question them? (Interview 3)

<table>
<thead>
<tr>
<th>HIV-related stigma (S)</th>
<th>I think just dealing with the ignorance and the stigma in the African American community I think it hinders me. (Interview 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class (C)</td>
<td>Um, my financial resources, I would love to do things a little differently like um, you know have like even the way I buy food you know like I would prefer to buy more fresh fruits and vegetables but that stuff is so expensive you know…(Interview 3)</td>
</tr>
<tr>
<td>Self-assessment of health (+)</td>
<td>And I’m not one hundred percent because I hate that medicine I ain’t going to lie - it is the worst. But for the most part I try to do what I do and just try to stay focused for them (Interview 3)</td>
</tr>
</tbody>
</table>

Figure 54: Vector Model for Eve
<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIGH</td>
<td>Oh yeah definitely I think that’s as matter of fact I know that’s why I’ve made it this far, because I don’t think if it was for them, I probably would have given up a long time ago. I have those days I’m just like I don’t want to do this I’m tired. But I have to remember my children so you know... that to me is a blessing and I look at it as if God knew, he knew that I would need that kind of motivation because if I did not have my children I'd probably just lay down in a corner somewhere just like leave me alone, let me die. (Interview 1)</td>
<td>I think it’s [HIV] made me more protective of my children. Um, just because I you know I want them to experience life but I also want them to have the best in life and I just think about, you know, the bad choices that I made you know, but the choices that I guess I wasn’t educated about. So now I make it my business to talk with them about certain things especially as far as like with my daughter about protected sex and taking care of her body and just being wise in the people she allows into her space but also it just makes me more protective of them and want to make sure that they have the best life they can have. (Interview 1)</td>
<td>I know that when I um, when I got pregnant with my daughter, I faced a lot of ridicule (Interview 3)</td>
<td></td>
</tr>
<tr>
<td>LOW</td>
<td>But you know some of the, some like my old pastor he never talked about the disease but he would always encourage me privately so umm, you know, he told me he said ‘you shall live and not die and declare the words of the Lord.’ And you know that was the thing that did it for me, and I haven’t been back in the hospital since, so… (Interview 3)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix N. Participant 005 (Laura) Vector and Frame Analyses

When I met Participant 005, she was residing in a small trailer home in a rural community north of the Research Triangle of North Carolina and this was the location of all three of her interviews. I will call her Laura. At the time of enrollment, Laura was 57 years old and reported having two children. She had been divorced twice and lived with her youngest child, a 14-year old girl. Laura reported being diagnosed with HIV five (5) years prior to enrollment in the study and acquiring it from her second husband whom she reported was unfaithful in their marriage.

I call this case “Being Positive,” not because Laura is HIV positive, but because throughout the interviews she repeatedly stated that she tries to maintain a positive outlook on life and that she “refuse[d] to look at the negative side anymore” (Interview 1). Laura attributed much of her positivity to her faith in God and being very spiritual. She had a church community, watched Christian television shows and enjoyed evangelizing at flea markets on the weekend. With regards to her HIV infection, Laura remarked, “But thanks be to God I don’t have to claim it. I can rebuke it in the name of the Lord” (Interview 1). Laura was not on anti-retroviral therapy and stated that she “try[ied] to stay away from doctors” (Interview 1), but that she felt very healthy. She stated, “Oh I feel wonderful, I feel wonderful every day. I get up every morning and thank the Lord” (Interview 1). Laura had not disclosed her HIV status to her daughter
and we verbally agreed during the consent process that we would refer to her HIV as her “chronic illness” or “her health” throughout the interviews in case her daughter should overhear us. She confirmed at all three interviews that she was amenable to this approach and that she was comfortable conducting the interviews with her daughter in her room. During the informed consent process Laura did not grant permission for the photographs of her and her daughter to be used for research presentations or publications.

All of Laura's photographs depicted positive determinants of health and focused primarily on her relationship with her daughter and the positive things they do together such as exercising, attending nutrition classes and recreating in local parks. Laura also identified her dog, her job as a nursing assistant and the many parks and activities offered in her community as positive determinants of health.

Table 20: Conceptual Model Social Determinants for Laura

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motherhood (~M)</td>
<td>She just, you know what it keeps me going. I mean to God be the glory for everything concerning my life I don’t want to talk down by no means, He is the one. But by Him putting this daughter in my life at this age, we just, she’s full of energy, we’re like a ball of energy together. (Interview 2).</td>
</tr>
<tr>
<td>Gender (~G)</td>
<td>I don’t think there’s no difference [between being a man or woman living with HIV] (Interview 3)</td>
</tr>
<tr>
<td>Race (~R)</td>
<td>As far as um...African American woman, I can say I’m glad to be who He created me to be (Interview 3)</td>
</tr>
<tr>
<td>HIV-related stigma (nd)</td>
<td>I feel like if I had the opportunity there would be some stigma there. But I guess I have you know, I haven’t- [experienced it]. (Interview 3)</td>
</tr>
<tr>
<td>Class (C)</td>
<td>Well not really, mm mm. I think that…I would have liked it as far as finances...about me being, I guess that would be because at one time we were getting child support but then he got disabled and we hadn’t and that’s between God and we’ve been doing that. So I guess you could say a little bit of finances, maybe. (Interview 1).</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Self-assessment of health (+)</td>
<td>Reported being healthy based on her definition</td>
</tr>
<tr>
<td></td>
<td>Health to me, is um….when you….health is when you feel good, and every part of your mind and body functions as it should. (Interview 3).</td>
</tr>
</tbody>
</table>

**Figure 55: Vector Model for Laura**
Table 21: Laura’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIGH</strong></td>
<td></td>
<td></td>
<td></td>
<td>No I think that’s-most of what you’re going to hear from me is positive and I think that I made it clear that that’s, but like I said I try to, I do what I can… It’s good to hear positive because like I said there’s so much negativity in the world anyway. …First thing I start doing is praising the Lord. There’s a scripture in the Bible about sustaining you. Your sleep will be sweet and he sustains you. (Interview 1)</td>
</tr>
<tr>
<td><strong>LOW</strong></td>
<td></td>
<td></td>
<td></td>
<td>Well let’s see… I guess, I feel like I’m not doing, there’s nothing that’s keeping me from taking care of myself. I just feel like it’s not… I mean I’m doing, well first of all I give honor to the man above. And other than him I just feel like I’m doing you know everything possibly (Interview 3)</td>
</tr>
<tr>
<td><strong>Not applicable</strong></td>
<td></td>
<td></td>
<td></td>
<td>Basically I’m just very spiritual like you said. And I just refuse to look at the negative side anymore. I told you, I guess you want me to hear about once when I was younger I did worry a lot I almost worried myself to death. And so I’ve learned, and I like to think that Christ, God has been the one that has showed me a better way to deal with if it was stress or anything I just basically let it go. I don’t worry, I don’t let nothing tie me down. I really cast it upon the Lord and I just deal with it and what’s done, that’s it I just won’t hold it with me. And I just basically stay in the positive, all around positive in everything. And I refuse to just, I refuse to talk about it, bring negativity or allow negativity in my life or my daughter’s life. And that’s how I deal and I feel that would be beneficial to somebody. (Interview 1)</td>
</tr>
</tbody>
</table>
Appendix O. Participant 006 (Rose) Vector and Frame Analyses

Rose’s full case was presented in the body of the text as an exemplar. Below is a reminder of the vector model constructed based on her case.

Figure 56: Vector Model for Rose
Table 22: Rose’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIGH</td>
<td>And I tried to base all my pictures on positive experiences. And that’s what the way I basically try to live day to day. On happy notes. (Interview 2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOW</td>
<td>But other than that, the other four reasons, I basically just don’t even try to put far as my race being an issue. Being a woman is not a issue. What other people will say is not an issue, but yea basically financially and eating more healthier will be the only one. (Interview 3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>Um, right now I’m at peace with it. It doesn’t complicate my days, I don’t have any side effects, I don’t really have any issues with it. Now that I’m on medication, and the medication is not giving me any kind of side effects that I need to deal with other issues outside of the ones I’m already dealing with and I do a lot of praying. And like I said I’m at peace with me, I know it’s something I would never get rid of but….I know other people that have other diseases and (crying)……and…. I was saying a lot of complications and I look at the sick patients that other people are going through and I’m like ‘mm, mine is nothing like that.’ (Interview 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix P. Participant 008 (Janet) Vector and Frame Analyses

When I met Participant 008 she was living in an urban area of the Research Triangle of North Carolina. I will call her Janet. One of Janet’s interviews took place in a private room at the university and two took place in her home. At the time of enrollment, Janet was 39 years old and reported living with HIV for eight (8) years. Janet was married, lived with her husband, was actively involved in her 11 year old stepdaughter’s life and was expecting a child. Janet worked in environmental services at a hospital. Janet relayed several stories about her daily interaction with her stepdaughter. Janet had disclosed her HIV status to her husband and immediate family members, but not to her stepdaughter. During the consent process, Janet consented to having her photographs used in research publications and presentations.

I chose to call this case "It has no effect on me" because on several occasions Janet stated that living with HIV had little to no impact on her life as a mother or her life generally. She also stated "...I mean it's not anything to broadcast. It's not hidden and it's not personal" (Interview 1). She reported her medication regimen was difficult for her to manage at one point in the past, but she described her current regimen by saying "the regime that I'm on now is excellent. I don't have any side effects so it's...it's great" (Interview 1). In general, Janet seemed to view living with HIV in a positive manner. She did a fair amount of reframing throughout her interviews. For example, she stated that
to her HIV “...is not a setback or a downfall to me. It is just something I got dealt” (Interview 3).

Janet reported difficulty in her reproductive life. She has wanted a child for several years and reported losing 3 previous pregnancies due to complications. She was in her third trimester while enrolled in the study and hopeful about the current pregnancy, Janet was visibly excited and joyful when she spoke about it. Janet seemed to have reconciled any negative feelings she may have had about her diagnosis with HIV and also her difficulty with maintaining pregnancies and wished to move forward.

All of Janet’s photographs focused on positive social determinants of health and the photographs (or intended photographs) primarily focused on her social support network, motherhood, healthy nutrition and transportation. Several of Janet’s photographs did not develop, so I asked her to recall some of the photographs she intended to take and why. At the time of the interview, Janet was 7 months pregnant and much of her photo elicitation interview focused on her impending motherhood. She linked each of the determinants she spoke about, except transportation, to her pregnancy. For example, she took photographs of healthful foods and related them to the health of both she and her child.

**Table 23: Conceptual Model Social Determinants for Janet**

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motherhood (~M)</td>
<td><em>Just excited about being a first time mom (Interview 1)</em></td>
</tr>
<tr>
<td>Gender (~G)</td>
<td><em>I mean, I’m not biased to say that women are stronger than men, but a lot of</em></td>
</tr>
<tr>
<td>Table</td>
<td>Description</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
</tr>
<tr>
<td>Race (nd)</td>
<td>Non-determinant</td>
</tr>
<tr>
<td>HIV-related stigma (nd)</td>
<td>non-determinant</td>
</tr>
<tr>
<td>Class (nd)</td>
<td>Non-determinant</td>
</tr>
<tr>
<td>Self-assessment of health (+)</td>
<td>Reported being healthy based on her definition</td>
</tr>
</tbody>
</table>
Figure 57: Vector Model for Janet
## Table 24: Janet’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIGH</td>
<td></td>
<td></td>
<td></td>
<td>Um, the first thing is that it could be worse. I could have a whole lot more stuff going on. I'm healthy, I’m able to work, I am going back to school shortly, ready to graduate from college. It is not a setback or a downfall to me. It is just something I got dealt. (Interview 3)</td>
</tr>
<tr>
<td>LOW</td>
<td></td>
<td></td>
<td></td>
<td>I would say how people treat me that know. Um, I thought when my, when some of my family found out that they were gonna you know “well don’t drink out of this glass, or do this or do that.” But they never did that and some of them are very, very cautious when it comes to, you know, people in and out of your house and doing stuff. But I mean, I’ve seen people get treated like “You can’t cook, you can’t eat here, bring your own cup.” And they’re stigmatized, but I don’t get that at all. (laughs) (Interview 3)</td>
</tr>
</tbody>
</table>
Appendix Q. Participant 009 (Shannon) Vector and Frame Analyses

When I met Participant 009 she was living in a duplex in an urban area of the Research Triangle of North Carolina and this was the location of all three of her interviews. I will call her Shannon. At the time of enrollment, Shannon was 36 years old and had three children: ages 17 years, 13 years and 7 years. Shannon was married and currently lived with her husband and her 7-year old son. Her 17-year old boy and 13-year old girl lived with their father. Shannon was diagnosed with HIV during her third pregnancy and reported that she had disclosed her HIV status to her husband but not her children. During the consent process, Shannon consented to having her photographs used in research publications and presentations.

I chose to call this case "You can live a long, happy life" because Shannon described a long, happy life as the endpoint to her journey of living with HIV. When she was first diagnosed, Shannon reported that she was very stressed by her HIV infection and the medications, but as time progressed her perception of her life circumstances changed. She reported that she now believes that if people become educated about the disease and take their medicine they can live long and happy lives. She stated, “But now I just know that I need to take care of my health. I need to stay on top of things. I need to eat healthier. I need to exercise. I need to really take care of myself. So that’s goes through my mind now” (Interview 3).
Shannon described motherhood as a positive health determinant since it inspires her to care for her health. She stated "I want to make sure I’m here for them as long as possible" (Interview 1). She acknowledged, however, that the tasks of mothering can sometimes make it difficult for her to care for her health and she finds hiding her HIV status from her children to be the most difficult part of parenting. She described having and raising her first two children as mostly difficult because she had little support from their father. She was young when she had them and she found it more difficult raising her second child, a girl. She also reported that her two older children do not currently live with her because she is concerned about the safety of the neighborhood they live in. She described having her third child as a "piece of cake" because she was older, had social support and didn't have to work. She also spoke glowingly about him and called him her “precious baby” (Interview 1).

When Shannon was diagnosed with HIV during her third pregnancy, she also learned her current partner (her husband and the father of the third child) was also HIV positive because he became very ill with AIDS. Although she spoke very positively with regards to mothering her third child and the support she received from her husband, she found the beginning of her course with HIV "stressful" (Interview 1) because her husband was sick, the medication made her feel sick, and she had very little flexibility for sick leave at her place of employment. She reported that at the time of the study,
both she and her husband were in good health and her perception of living with HIV has shifted to a much more positive outlook.

Shannon primarily focused on negative health determinants or mixed determinants, having both positive and negative qualities, in her photographs. For example, she took a photograph of her medications and stated the following when describing the photograph "Well it's hard to take 'em every night, but I know that it's good for my health and it'll keep me around longer to take care of my little ones....I know it's gonna help me but I don't like it” (Interview 2). Shannon spoke at length about hiding her HIV status from others during the photo elicitation interview and took photographs representing her attempts to do just that. For example, she took a photograph of her bathroom mirror and described how she puts on make-up and tries to hide her HIV from the world. Shannon linked her attempts to hide her HIV status and her difficulty in facing the outside world to HIV-related stigma. She stated, “I still have a stigma about it - so it's hard to go out to the world...I'm too ashamed or embarrassed” (Interview 2).

Shannon took one photograph that she reported solely a positive health determinant and that was a picture of trees, representing nature or physical environment. She stated, "...I kind of started appreciating it more after knowing you know I was diagnosed...” (Interview 2)
### Table 25: Conceptual Model Social Determinants for Shannon

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motherhood (~M)</strong></td>
<td><em>I try to eat things that are healthy and they build my immune system. And I do things that will keep my viral load down by taking my medicine on time every day because I want to make sure I’m here for them as long as possible.</em> (Interview 1)</td>
</tr>
<tr>
<td><strong>Gender (~G)</strong></td>
<td><em>Well being a woman that’s well-spoken. I don’t really bite my tongue a lot but I’m- I’m filtered. Um, I do have a little more than GED education. I have some college, so that helps me be able to understand some of the phrases and words that other people in higher places use. And sometimes it lets them know, ‘Okay, well maybe she can fill this position.’ So that kind of makes me feel a little bit better to know that I’ve had some kind [of] college and I have a pretty good vocabulary</em> (Interview 3).</td>
</tr>
<tr>
<td><strong>Race (R)</strong></td>
<td><em>Well um, not going with statistics I think it’s a little harder cause a lot of African-Americans don’t actually finish school or get their GED’S and go to college. I did end up doing those things but after my first baby, but I never went to continue my education. So I think it’s a lot harder, I’m not sure. This is without statistics; this is without a little research and everything. But just looking from the inside out and sometimes outside in, it seems to be a little more difficult</em> (Interview 3).</td>
</tr>
<tr>
<td><strong>HIV-related stigma (S)</strong></td>
<td><em>I still have a stigma about it - so it’s hard to go out to the world...I’m too ashamed or embarrassed.</em> (Interview 2)</td>
</tr>
<tr>
<td><strong>Class (~C)</strong></td>
<td><em>Yeah I do feel like I have the resources I need for that. Medication is free. Um, they mail it right to the door. Um, my appointments are free; they are not way in [name of city] or [another city] somewhere. So yeah I think I have the resources that I need to take care of myself pretty well</em> (Interview 3).</td>
</tr>
</tbody>
</table>
Figure 58: Vector Model for Shannon
Table 26: Shannon's Frame Analysis: Exemplar Quotes

| Participant
| Motherhood perceived as buffer to HIV | HIV perceived as enhancing maternal identity/relationship | Social determinants perceived as deleterious to health | Reframing |
|---|---|---|---|---|
| 009 Situational Frame |
| **HIGH** | Well it’s hard to take ’em every night but I know that it’s good for my health and it’ll keep me around longer to take care of my little ones. (Interview 2) | Um, I guess to cherish every moment that she could with her children cause that’s- that’s kind of what I’m doing now. Every moment is very special to me. (Interview 3) | Now, that [being AA mother living with HIV] just doubles the stress Um, with it not being known it’s a lot easier. If it was known I don’t think it would be very easy at all. (P laughs) Um, I don’t know it’s kind of hard to explain but it just add to the stress. (Interview 3) | |
| **LOW** | | | | I don’t think it’s as bad now. Um, I think I’m getting older and maturing and a lot of times it really doesn’t matter what other people think because they’re not taking care of you or your family. So it’s kind of like whatever now. (P laughs)... I just gotta take care of us. (Interview 3) | |
Appendix R. Participant 011 (Tammy) Vector and Frame Analyses

When I met Participant 011 she was living in an urban area of the Research Triangle of North Carolina and all three of her interviews took place in a private room at the university campus. I will call her Tammy. At the time of enrollment, Tammy was 41 years old and had three male children - ages 22, 16, and 5 years old. Tammy was single and she currently lived with her 16 year old and 5 year old. Tammy was diagnosed with HIV during her pregnancy with her youngest child and had not disclosed her HIV status to anyone other than her healthcare providers. During the consent process, Tammy consented to having her photographs used in research publications and presentations.

I chose to call this case "I have to do what I have to do" because this is how Tammy described her efforts to care for her health for the sake of her sons. A main storyline in Tammy's interviews was how she had to really pick herself up after her HIV diagnosis and do what she needed to do in order to take care of herself. Tammy described motherhood as a motivation and positive social determinant of health. She reported that when she found out she was pregnant with her third child and also found out she was HIV positive she went into "mama tiger mode" (Interview 1). She then stated, "I know I have to take care of my kids and I actually feel like I go even harder for them knowing my diagnosis" (Interview 1).
While Tammy described motherhood as a motivation to care for herself and her health, she also relayed many stories about how difficult it was for her to hide her diagnosis from her children. She reported hiding all her pills in other medicine bottles and lying to her children and others about what they are for. She linked her silence to the stigma that she feels associated with the disease. At one point she relays a story about the stigma she feels from her own son. Her eldest son joked about people with HIV, saying they have 'that thing' or 'the monster' (Interview 1) and it made her feel “ashamed” (Interview 1). Tammy's reluctance to share her HIV status with anyone had led to some difficult situations for her and her family. At one point she reported they became homeless because she was feeling depressed, didn't want to tell people about her illness and didn't reach out for help.

Tammy reiterated several times during the interview how she tried to reframe the situation for herself. At one point she talked about a social worker coming to her home and she ultimately concluded that she just needed to “shut the hell up, get up, do what you got to do, take your medication” (Interview 1). She did report reframing her situation in the context of a spiritual belief and never mentioned being "positive," rather doing what she deemed as necessary.

Tammy primarily focused on positive social determinants of health in her photographs, with the exception of a photograph of the rain that she described as
representing her concern about accessing her medications. At the time she took the photograph she was reapplying for the AIDS Drug Assistance Program (ADAP) and was concerned it would not be renewed. She then went on to discuss that her children have Medicaid but she only has it for family planning, and she feels she could use assistance with health coverage. Tammy was working full-time for an airline, but access to healthcare was a concern for her. Otherwise, Tammy took pictures that she felt represented positive health determinants such as nature, her children (although we couldn’t keep these), her housing and her job. Tammy pointed out the sunshine in one of the pictures and said, "That was basically just showing that there’s brighter days in my future... HIV doesn’t stop your life, basically that’s what I’m trying to say" (Interview 2).

Table 27: Conceptual Model Social Determinants for Tammy

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motherhood (~M)</strong></td>
<td>I know I have to take care of my kids and I actually feel like I go even harder for them knowing my diagnosis (Interview 1).</td>
</tr>
<tr>
<td>Identified as her most positive social determinant of health</td>
<td></td>
</tr>
<tr>
<td><strong>Gender (G)</strong></td>
<td>That it’s, it’s hard and well me personally, I don’t know how other people deal with it but I think I’m secretive about it because I don’t want that stigmatism (Interview 3).</td>
</tr>
<tr>
<td>When asked about her experience of being a woman living with HIV, she linked her gender to stigma</td>
<td></td>
</tr>
<tr>
<td><strong>Race (R)</strong></td>
<td>You can’t pick up something or that’s wrong to say, you do pick it up ‘cause you see it, but you’re not born with it [racism] instilled in you. You learn it as you go and to me that’s just bull hockey, excuse my French. (laughs) Sorry to have that on a recording...It just pisses me off (Interview 3).</td>
</tr>
<tr>
<td><strong>HIV-related stigma (S)</strong></td>
<td>I hate hiding but at the same time I feel like it keeps me safer and saner because I’m an out going person and I would hate to be ostracized (Interview 3).</td>
</tr>
<tr>
<td>Identified as the most detrimental social</td>
<td></td>
</tr>
<tr>
<td>determinant of health</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td></td>
</tr>
</tbody>
</table>
| **Class (C)**  
Recalled story of feeling discriminated against for her class |
| Unfortunately it was more Caucasian-type neighborhood but I was just close by there and it was something that I wanted to get from out of the store and I felt they were looking at me like okay do you know how much this is going to cost? That kind of thing. And I hate when people do that because you don’t know anyone’s situation and you don’t know when you can be in that situation, so don’t look down on anyone else and their financial situation. Just ‘cause I was receiving food stamps it doesn’t mean I’m not working or working to work towards being back in the work force. (Interview 3) |

| **Self-assessment of health (+)**  
Response when asked to define health or being health |
| P: Me. The end. (Laughter)  
I: …So based on your definition do you consider yourself healthy?  
P: Yes ma’am. |

---

*Figure 59: Vector Model for Tammy*
### Table 28: Tammy’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIGH</strong></td>
<td>A very happy child. Photogenic and those dimples and eyes. They pull me in every single time. But, as I explained earlier, he is the one that I was pregnant with when I was diagnosed the first time and he’s the reason I live. And he’s the reason I’m undetectable now. (Interview 2)</td>
<td>So yes, I might baby him a little more than I did the other two but the ones will understand until I let them know what me and him have went through. And I think that’s what the extra connection is too. Because not only did I have to think about myself I had to think about him inside of me. This innocent child that didn’t know, ‘listen mommy’s sick or whatever.’ Even now he doesn’t know. To him I’m the perfect mother, which I am really, but you know still got that little whatever going on. (Interview 2)</td>
<td>Um. Yes. I can honestly say that [stigma has prevented her from seeking health care]. At first I was about to say no. But yes, because when I had moved from [city1] to [city2] I was going crazy trying to figure out a clinic to go to where people wouldn’t see me who let’s say live around my block. (Interview 3)</td>
<td></td>
</tr>
<tr>
<td><strong>LOW</strong></td>
<td>I was going to take a while long before I accepted it but she gave me that ‘mmmm’ let’s do this. Let’s get this together, you’re pregnant. Even if you don’t care about yourself and that’s exactly how blunt she spoke of me too ...But she happened to tell me that she was diagnosed twenty five years ago and she’s basically showing me, look I’m here and I’m still alive. So get up off you ass and let’s do this. So I was like wow, okay. (Interview 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix S. Participant 012 (Ophelia) Vector and Frame Analyses

Ophelia’s full case was presented in the body of the text as an exemplar. Below is a reminder of the vector model constructed based on her case.

Figure 60: Vector Model for Ophelia
### Table 29: Ophelia’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIGH</strong></td>
<td></td>
<td></td>
<td>Well with me, I feel that um, we can’t do things normal. When I mean normal, like ah, companionship. You just can’t um, it stresses me out and like I got a husband, you know what I’m saying, but he’s not HIV positive. But what I went through— is trying to explain to him about my disease. I mean he’s accepted me but whenever I end up I meeting somebody else and I have to tell them the whole story, that’s stressful for me. So I feel after my husband I would not be with another man ‘cause I don’t want to put myself back through that trying to explain to this man about my disease, put up with his family, put up with all that. And then I feel that when a person is like in my predicament people take advantage of me, especially your companion. (Interview 3)</td>
</tr>
<tr>
<td><strong>LOW</strong></td>
<td>Oh, God it’s always so like, fussing and not doing their homework like they’re supposed to. Just not doing- not doing what they supposed to- especially they teenagers you know what I’m saying? They not doing what they supposed to do. But um, it just bothers me because I know they—I have to take care of ‘em and whatever happens to ‘em is gonna fall back on me. They don’t realize that, they don’t realize it affects me mentally, you know what I’m saying? … I take me an afternoon nap, whenever I have to take ‘em. I have- I don’t want to snap on one of ‘em you know what I’m saying? They don’t understand dealing with this disease and still I get on ‘em- sometimes I used to forget to take my medicine, you know what I’m saying? And that would be stressful out. (Interview 1)</td>
<td>Well it depends how- I mean I guess it’s stressful to me. But I don’t let my grandkids know you know what I’m saying? I’ve be under stress. I am going through so much I just don’t say nothing. I keep a lot in. Sometimes you talk to your family, they don’t understand. I rather go out and talk to [healthcare worker], my mental health doctor, my case manager. I call them ‘cause when I talk with my family they always give me negative feedback but I’ll ask them just to listen. I don’t want no feedback, ”just listen so I can get this out.” (Interview 1)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix T. Participant 013 (Connie) Vector and Frame Analyses

When I met Participant 013 she was residing in an apartment in a small town north of the Research Triangle of North Carolina and this was the location of all three of her interviews. I will call her Connie. At the time of enrollment, Connie was 30 years old and had three children: ages 10 years, 2 years and 1 month. She was living with her partner who was the father of her third child. Connie had been living with HIV for seven (7) years and had disclosed her HIV status to her partner and immediate family, but not to her children. During the consent process, Connie consented to having her photographs used in research publications and presentations.

I chose to call this case "I lost a lot of friends but I gained much more" because Connie described her journey of living with HIV in this way. Connie was in the throws of parenting young children and was 4 weeks postpartum from her third child. Connie openly shared her struggles with parenting and often shared the negative aspects of the role during the interview. She began by expressing the fear she had about being an HIV-infected mother and passing the virus to her children. She stated "And a lot of mothers chew their babies food and stuff, I didn’t never do that with him cause I was scared" (Interview 1). Connie spoke openly about her frustration her children, disciplining them and making time for herself. Connie also relayed many positive stories about mothering and the "joy" her children bring to her life (Interview 1). Connie reported motherhood
was a motivation for her to care for herself. For example, at one point she stated, "...sometimes I feel like giving up. But then I say, 'I know I got a reason to live for. Three beautiful reasons. The little ones’’” (Interview 2).

When asked about being diagnosed with HIV, Connie said that when she received the diagnosis that "I didn't want to live. I really didn’t” (Interview 1). She relayed stories about how she felt stigmatized by others in the small town where she lived and by her stepfather who insisted she eat from separate plates in his home.

Connie also reported receiving a good deal of social support. She reported that her mother was very supportive when she disclosed her HIV status to her (a month after her diagnosis) and ultimately her stepfather also became supportive. She stated, "I have a lot of support with that - they don't judge me” (Interview 1). In the past, Connie's reported that one of her concerns about being HIV positive was not having a partner and she stated that "I didn't think I was ever going to have a man” (Interview 1). She reported, however, that she currently has a supportive partner, the father of her third child. He described him as a very positive person in her life, encouraging her to take care of herself and also helping with the children.

Connie reported struggling with taking the HIV medication because it serves as a daily reminder of her HIV. She stated "I am tired of taking medicine” (Interview 1) and wished that someone would invent a pill that could be taken every six months. Connie drew strength from being a mother in order to cope with her medications. She stated,
“...sometimes I just don’t feel like taking it. I'll be like- I think to me- I still got a reason to live cause of my little ones. I just be like-I’m tired of taking medicine” (Interview 1).

Connie primarily focused on positive health determinants in her photographs, with the exception of a photograph of the floor in her apartment that she described as representing her “down days” and her telephone that she interpreted as representing the time period when she was first diagnosed with HIV. She reported that she “had to call everybody you know that I messed with and stuff- and let them know what happened and I really didn’t want to...they abandoned me” (Interview 2). Connie took several photographs that represented her positive outlook on living with HIV. Examples included: a picture of a calendar representing that she has made it another year, a picture of a door representing that she has conquered her fears about going out the door with HIV, a picture of the fall leaves representing that she has overcome many obstacles and a picture of the bathroom mirror representing that she is still living. Connie reported her religion and her faith as being important in her life as well. She said she prayed when she was down and tried to remember that "everything happens for a reason" (Interview 2). She also took a picture of the bulletin of her church bulletin and reported the members at her church were nonjudgmental and welcomed everyone.
<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motherhood (-M)</strong></td>
<td><em>It might be hard but I think we living for our little ones. I think that’s what gave ’em probably strength to get up every morning</em> (Interview 3)</td>
</tr>
<tr>
<td><strong>Gender (G)</strong></td>
<td>Um, I think it’s probably harder than a man. (interview 3)</td>
</tr>
<tr>
<td><strong>Race (nd)</strong></td>
<td><em>I guess it’s not different from being a Caucasian mother</em> (Interview 3)</td>
</tr>
<tr>
<td><strong>HIV-related stigma (S)</strong></td>
<td><em>I think it was because I had HIV, that’s what I still think it was</em> (Interview 3)</td>
</tr>
<tr>
<td><strong>Class (C)</strong></td>
<td><em>I’m very conservative too even though I’m on a limited-income. I wasn’t raised with the best so I’m not trying to raise my child like that. Even though I still want her to have a lot of stuff. I don’t want to raise her like you know, “You got to have this and you got to have that.” Because there’s people around here that does that. “Cause when you get older you gonna have to work for all that stuff and Mom ain’t gonna be around for that. So.” Sometimes I think it is like people like, “Well you shouldn’t be out this and you shouldn’t be out of that.” But I’m like- well I mean I have bills to take care…</em> (Interview 3)</td>
</tr>
<tr>
<td><strong>Self-assessment of health (+)</strong></td>
<td><em>Taking care of yourself, eating right, exercising. Ah, when the doctors said, “Don’t smoke cigarettes.” (laugh) And I said, “They didn’t tell me to stop. They want to take drinking from me.” Cause I was- I was using drugs too so you know? So they took that away from me and then wanted to take the cigarettes away from me. But I said, “One thing at a time.” And I guess just living right and believing that everything happens for a reason and just having faith</em> (Interview 3)</td>
</tr>
</tbody>
</table>
Figure 61: Vector Model for Connie
## Table 31: Connie's Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIGH</td>
<td>I know I’m supposed to take it like at a certain time everyday- I’m supposed to eat with it but-sometimes I think sometimes I just don’t feel like taking it. I’ll be like- I think to me- I still got a reason to live cause of my little ones. (Interview 1)</td>
<td>Cause a lot of people probably would have gave up. I wanted to give up at one time. I’m like- I didn’t but then I said- I thought about it I said, ’ I got a child you know who’s going miss me and who loves me. So- I think that’s the whole- keeping me holding on- is my kids. Cause I probably would have- I probably would have gave up years ago. I said, ’Everything happens for a reason. There’s a reason why I’m still here.’ (Interview 3)</td>
<td>VARIABLE FOR HER: But I don’t think I have been treated different. I know a lot of people- when I got pregnant they were shocked like ”How do you get to have a baby and have HIV?”(Interview 3)</td>
<td>So I just have to look at the good side of things like I got my health, I got a place to stay. I mean what more can I ask for? A lot of people don’t have this. (Interview 3)</td>
</tr>
<tr>
<td>LOW</td>
<td>VARIOUS FOR HER: But I don’t think I have been treated different. I know a lot of people- when I got pregnant they were shocked like ”How do you get to have a baby and have HIV?”(Interview 3)</td>
<td>VARIABLE FOR HER: But I don’t think I have been treated different. I know a lot of people- when I got pregnant they were shocked like ”How do you get to have a baby and have HIV?”(Interview 3)</td>
<td>VARIABLE FOR HER: But I don’t think I have been treated different. I know a lot of people- when I got pregnant they were shocked like ”How do you get to have a baby and have HIV?”(Interview 3)</td>
<td>VARIABLE FOR HER: But I don’t think I have been treated different. I know a lot of people- when I got pregnant they were shocked like ”How do you get to have a baby and have HIV?”(Interview 3)</td>
</tr>
</tbody>
</table>
Appendix U. Participant 016 (Camille) Vector and Frame Analyses

Camille’s full case was presented in the body of the text as an exemplar. Below is a reminder of the vector model constructed based on her case.

Figure 62: Vector Model for Camille
<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIGH</td>
<td>Cause I know I have to take care of myself cause I have to live for someone- live for someone else like I have to be there regardless. So I have to take care of myself, to keep going on, to be all I can for him. I got to keep my health together.(Interview 1)</td>
<td>Cause I don’- I you know being a mom you want to be there, you don’t want no one else to raise your child but me. I want to raise my own child, so I just thank God for giving me another chance to go on (Interview 1)</td>
<td>Bills can make you sick.(interview 3)</td>
<td></td>
</tr>
<tr>
<td>LOW</td>
<td></td>
<td></td>
<td></td>
<td>Realize life's too short. You don’t need to have that negativity all the time. Things gonna happen, that’s life. But you got to fight through it.(Interview 1)</td>
</tr>
</tbody>
</table>
Appendix V. Participant 017 (Kara) Vector and Frame Analyses

When I met Participant 017 she was living in an urban area of the Research Triangle of North Carolina and all of her interviews took place in a private room at the university campus. I will call her Kara. At the time of enrollment, Kara was 46 years old and the guardian of her 6 year old grandniece. Kara was married but did not live with her partner and she described it as a negative the relationship. She stated, "we stayed on together. I still don’t like him but it is what it is" (Interview 1). Kara and her grandniece lived in a home with Kara’s sister. Kara had been living with HIV for 14 years and had not disclosed her HIV status to her grandniece, although most of her immediate family was aware of her HIV status. During the consent process, Kara did not consent to having her photographs used in research publications and presentations.

I chose to call this case "I'll just learn to ignore it" (Interview 1) because Kara’s statement seemed to sum up how she felt about living with HIV. Indeed, Kara reported that living with HIV was not one of her greatest concerns. Kara was wheelchair bound and had multiple comorbidities including a history of drug addiction and several physical disabilities. Six months prior to enrolling in the study she had her left leg amputated due to an injury and her left arm remained in a brace. Much of Kara’s focus during the interviews was on these concerns and how they impacted her role as a mother, moreso than HIV. For example, during the first interview I asked Kara to tell me
what ways, if any, having HIV had impacted her being a mother and she chose to talk about how her physical disabilities instead of living with HIV. She reported that it was quite difficult for her to logistically manage the tasks of motherhood like cooking, bathing the child, doing dishes, transporting herself and the child, and playing with her. She also reported that being a mother made it quite difficult to manage her healthcare as she had to schedule her appointments around her grandniece's school day. Kara also described that she and her grandniece had experienced stigma secondary to her disabilities. It was at this point in the first interview that Kara described some of the positive aspects of mothering her grandniece and how she taught her grandniece different things like how to "turn the other cheek" when other people teased her (Interview 1). Kara reported learning this lesson herself from her experience of living with HIV. Kara reported feeling "devastated" when learned of the diagnosis and described experiencing HIV-related stigma early on. She reported that she had acquired it from her husband and that he had not told her that he was infected. Kara described that at some point in the past fourteen years her perception of the disease changed and she thought, "Well, I'll just learn to ignore it. Because I don't feel like I got it. I don't look like I got it. Actually every morning I get up I feel good" (Interview 1). Kara also reported that mothering helped her to manage her substance abuse. She stated, "It feels good. It really does. I have more of a responsibility to not want to use. So each day is a challenge and it- it- it don't beat me down like, 'Oh I can slip and do it while she in
school.' No, I just don’t want to do it. And I feel much better afterwards I can do a lot more with her. It feels real good” (Interview 1).

Few of Kara’s photographs related to living with HIV. Again, Kara’s primary health concern was her physical disabilities and how living with an amputated leg negatively impacts her day-to-day circumstances. When asked, Kara confirmed that living with her physical disability was more difficult than living with HIV. She attributed this to two things - feeling burdensome and disability stigma. She stated, "So I would say it’s more managing my health with my leg cause I feel more let down. Don’t nobody want to be around me or I’m a hindrance to a lot of people. Because if I go somewhere I got to be ahead of them or I’m slowing them down. I’m too slow” (Interview 2). Kara then went on to describe the stigma she feels from having an amputated leg and stated "But um, I- I say it's more with my leg because people look at me funny too and then they stare. They don’t look, they stare.” (Interview 2).

Table 33: Conceptual Model Social Determinants for Kara

<table>
<thead>
<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Motherhood (~M)</strong></td>
<td>Ah, I know how to better handle the finances, better not use. Teaching my niece, my great-niece right and wrong, how to be a young lady well a little girl right now, then becoming a young lady. Cause before long she’ll be in the double digits and when they in the double digits they fly away from you. (I laughs) So yeah, teaching her and then teaching her not to be mean to people, and don’t do that and you don’t call people bad names and call them out their color (Interview 3)</td>
</tr>
<tr>
<td><strong>Gender (G)</strong></td>
<td>Well it’s very hard due to um, I think people stare at me and um, when I go to the doctor um, well I’ve learned a lot about it by me living with it and being a woman. Um, when I go to my primary doctor at the Health Department um, there are different things that goes on with a woman. (Interview 3)</td>
</tr>
<tr>
<td><strong>Race (nd)</strong></td>
<td>No. (Interview 3)</td>
</tr>
<tr>
<td>Does not directly answer questions regarding race/racism except the direct question of whether she had ever experienced racial discrimination</td>
<td>…it used to make me to where if I got mad or anything like that I would go and use. It would be the only thing that would kick me out or if I had money too. Them two things would trigger me wanting to go get high, other than that, nah. I would be just fine. (Interview 3)</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>HIV-related stigma (S) Identified as most detrimental social determinant of health – linked it to her drug addiction</td>
<td>But I feel as if the government is giving everybody what they supposed to have. If you feel that you need some more, you need to go to work you don’t need that money ‘cause you all should be able to budget, and my sister has taught me that a lot. (Interview 3)</td>
</tr>
<tr>
<td>Class (~C) Talks at length about social programs</td>
<td>I define it as mine is excellent. I wish my sister could get herself to check-with her health. She don’t eat right. She’s a vegetarian. My- me I get my three square meals ‘cause I go to my momma in the morning, I get my breakfast; I get my lunch there unless I have an appointment like now. Till I stop off at McDonalds, then I don’t eat the French fries. I don’t usually buy the fried foods. I would eat the hamburgers but I’m gonna stop that and just get a salad and crumble my hamburger up in it. But I don’t have to have a meat salad but other than that I get square meals and I’m getting a lot of proper rest….Yeah, that has a lot to do with HIV. ‘Cause if you tired, your body is tired, your brain is tired. You cannot function, can’t remember.(Interview 3)</td>
</tr>
<tr>
<td>Self-assessment of health (+)</td>
<td></td>
</tr>
</tbody>
</table>

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Figure 63: Vector Model for Kara
### Table 34: Kara’s Frame Analysis: Exemplar Quotes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
<th>HIV perceived as enhancing maternal identity/relationship</th>
<th>Social determinants perceived as deleterious to health</th>
<th>Reframing</th>
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<tr>
<td>017 Situational Frame</td>
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<td>VARIABLE FOR HER (SEE ABOVE) Well it’s very hard due to um, I think people stare at me and um, when I go to the doctor um, well I’ve learned a lot about it by me living with it and being a woman. (Interview 3)</td>
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| HIGH | With her, every day is an important point cause every day is a different adventure. ... Over the last four years. It’s- every day is a different adventure...It feels good. It really does. I have more of a responsibility to not want to use. So each day is a challenge and it- it don’t beat me down like, ‘Oh I can slip and do it while she in school.’ No, I just don’t want to do it. And I feel much better afterwards I can do a lot more with her. It feels real good. [had reported that when she got angry about her HIV she would use drugs in the past] (Interview 1) | And I’m like, “You don’t do that to other people because if something is wrong with you-you don’t want them to do it to you.” So I think she remembers that each time somebody wants to say something to her bad or something. She just turns the other cheek and walk away. So I pretty much taught her that part though, because I got the anger behind it myself and when people were saying that I had HIV- (Interview 1) | Praying, like I supposed to, I say a prayer in the morning or a prayer in the evening and a prayer at night. It get’s me through. I don’t let no negativity bounce on me and stay on me. I let it bounce off of me cause I’m not trying to be you know around that and negativity can bounce on you. It’s like electric; just want to keep on being there. No, cause somebody else having a bad day doesn’t mean they should up right someone else’s good day. (Interview 3) | |
| LOW | | | | |

(VARIABLE FOR HER (SEE ABOVE) Well it’s very hard due to um, I think people stare at me and um, when I go to the doctor um, well I’ve learned a lot about it by me living with it and being a woman. (Interview 3) | | | |

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Appendix W. Participant 018 (Erin) Vector and Frame Analyses

When I met Participant 018 she was living in an apartment in an urban area of the Research Triangle of North Carolina and this was the location of all three of her interviews. I will call her Erin. At the time of enrollment, Erin was 26 years, married and had five children: ages 7 years, 6 years, 5 years, 3 years and 4 months. Erin was diagnosed with HIV during her pregnancy with her oldest child and she had disclosed to her husband but not to her children. During the consent process Erin originally requested that her photographs not be used in research publications and presentations but after participating in the photo elicitation exercise she called me and requested to change her consent form. We reviewed and signed a second consent form indicating this change.

I chose to call this case "It has its up and down moments" because Erin described both motherhood and living with HIV as variable - having both positive and negative aspects. Erin was emotional throughout her interviews as she described the positive and negative aspects of her life circumstances. For example, she explained her conflicting emotions when she found out she was both pregnant and living with HIV by stating, "...I was pregnant with my first son I was- I was happy and sad at the same time because I found that I was positive..." (Interview 1) She went on to describe her diagnosis with HIV as "devastating," particularly because her infection was a result of sexual assault.
She stated while crying "It's like a double dose of...bad. It is difficult" (Interview 1).

When reflecting on her current perception of living with HIV, however, she stated, "Well my self-esteem has gotten better about it now. Now I have my husband, a good support system to help me cope every day. My children are a blessing so that's even better to move forward and get me a reason to move forward" (Interview 1).

In terms of motherhood, Erin also viewed this role as variable - with positive and negative aspects. She reported that the sheer logistics of raising five children - managing their appointments, arranging transportation, etc. - was difficult and “hectic” (Interview 1). Erin also pointed out many positive aspects of mothering - her children's smiles, the fact that they are HIV negative and that they were a "blessing" to her (Interview 1).

Erin’s reported that her children motivate her to care for her health. She described making sure she took her medication during pregnancy and how happy she was that her children are HIV negative.

Erin focused almost exclusively on positive health determinants in her photographs and the vast majority related to her children and the positive aspects of being a mother. She took pictures of her children’s toys, books, and feet, as well as the calendar she used to organize their appointments. Over and over again, she described motherhood as positively impacting her mental health and stated that her children made her "happy" (Interview 2). She also took other photographs (for instance, the picture of her medications) that she linked to motherhood. She identified her medications as
"definitely a strength," and said she took the medication to maintain her health because "Um, well I have to take it so I can be you know healthy and strong for my kids" (Interview 2). Other positive social determinants of health represented in Erin's photographs included: her health providers, her physical environment, the ability to communicate with loved ones via her cell phone, her pets and her social support network. For example, she took a photograph representing her husband and stated "And it symbolizes him you know just being a strong individual in my life and giving me the support that I need.... yeah because he's- he encouraged me a lot to keep up my health" (Interview 2).

Erin took one photograph that she interpreted with a more mixed or negative connotation. It was a picture of a door and she said, "And just people outside of that door that you know that are just mean and negative. I don’t think everyone is understanding." (Interview 2). She seemed to be talking about HIV-related stigma but then qualified her statement by saying" Mm, it's not- it's not a strength but- but it's not a concern either...because regardless, I have to maintain my health for my children and I ignore the negative" (Interview 2).

<table>
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<tr>
<th>Determinant (s)</th>
<th>Exemplar Quote</th>
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<tr>
<td><strong>Motherhood (~M)</strong>  Identified as most positive social determinant of health</td>
<td><em>I mean, I had- I had a horrible childhood growing up with the typical abuse, rape and all of that and um, to strive (P starts to cry) I’m sorry....To strive and do the total opposite of what you’ve been through- but you have to have a strong mind and a strong heart to do it cause I have been through some things that I shouldn’t even went through. You can’t use what you went through as a crutch and I was just one of the ones that refused to. And having my</em></td>
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<td><strong>Gender (nd)</strong></td>
<td>No, not so much because I’m a woman, more so just because I’m positive. (Interview 3)</td>
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<td><strong>Race (nd)</strong></td>
<td>I don’t know. I don’t know. I just- I’m a mother you know? I know there are a lot of stipulations to- that people say being Black and all of that but I don’t live like that. I don’t- I don’t follow the stipulations or believe that we still live in a time of racism- which we- there are people that could still be racist but you know I just try to see the good in everything and in everybody (Interview 3)</td>
</tr>
<tr>
<td><strong>HIV-related stigma (nd)</strong></td>
<td>Um, I guess the HIV stigma but I’m gonna do me regardless. (P laughs) I have a- a drive and a purpose and none of those can- that’s on that list can affect me. (Interview 3)</td>
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<td><strong>Class (nd)</strong></td>
<td>Yes and no. Probably so probably just didn’t recognize it (Interview 3)</td>
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| **Self-assessment of health (+)** | Stated she considered herself healthy based on her definition, but if she had been asked in 2000, she would not have considered herself healthy

...active all the time, stay active and eating right you know? Not filling your body up with junk and sweet beverages all the time- the quickest, easiest things to eat are always the worst things that can affect your health you know? Um, having regular doctor visits, check-ups you know? To make sure everything is in line and being a women- having breast check-ups and all of that is very important for your body and for you. (Interview 3)
Figure 64: Vector Model for Erin
### Table 36: Erin's Frame Analysis: Exemplar Quotes

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<tr>
<th>Participant</th>
<th>Motherhood perceived as buffer to HIV</th>
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<tr>
<td><strong>HIGH</strong></td>
<td>Because regardless, I have to maintain my health for my children and I ignore the negative. (Interview 2)</td>
<td>Their smiles. (P laughs) They’re—they’re very happy children and just to know that I was—I was able to have children that were born HIV free. That gives me the urge to take care of ’em more and more every day. (infant makes noise) (Interview 1)</td>
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<td><strong>LOW</strong></td>
<td>I have a drive and a purpose and none of those can—that’s on that list can affect me. So—(Interview 3)</td>
<td>You think, you have so many questions and whether they are good and bad, but you can live, that’s one thing you can do, you can live and you still can be your regular self you just have to chose the type of people who are—what do I say? Who are—who are for you and have those type of people in your life. Because if not they—they will push you to the brink of making yourself feeling even worse than what you do. (P crying) And it’s not worth it, it’s not. I been there, I went through it so I know. I’m only saying it from experience. (Interview 1)</td>
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References


an intervention for parents living with HIV and their adolescent children. *AIDS, 17*, 1217-1225.


Biography

Courtney Ellis Caiola was born in Fayette, Missouri on June 7, 1970. She is the daughter of Dr. Larry Ellis and the late Marie Ellis. Courtney is married to Jeffrey Caiola and has three children – Ellis, Marie and Gabriella Caiola. Courtney earned a Bachelor of Arts degree in Anthropology and Biology from the University of North Carolina Chapel Hill in 1992, a Master of Public Health from Tulane University School of Public Health & Tropical Medicine in 1994, a Master of Nursing from the University of Tennessee Knoxville in 1997 and is currently a PhD candidate in the Duke University School of Nursing. Prior to starting her doctoral training, Courtney worked as a registered nurse both domestically and globally for 13 years. Courtney received funding from the Jonas Center for Nursing Excellence and was selected as a Scholar in the Jonas Nurse Leaders Scholar Program. She also received a grant from the National Institutes of Health, an individual national service award (NRSA) as a pre-doctoral fellow. Courtney is the first author on two published manuscripts, one manuscript in press, and has a third manuscript under review. She is also a co-author on two articles:


Caiola, C., Docherty, S.L., & Barroso, J. (under review) One size does not fit all: Tailoring a visual methods protocol for mothers living with HIV. *Qualitative Health Research*.
