

# INTERSECTIONALITY OF IDENTITY AND HIV-RELATED STIGMA

by

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## ABSTRACT

LAURA VANESSA LOVATO. Intersectionality of identity and HIV-related stigma.  
(Under the direction of DR. AMY PETERMAN)

The impact of HIV-related stigma on HIV prevention, treatment, and the well-being of people living with HIV (PLWH) is well established within the existing literature. HIV-related stigma experiences are compounded by intersections of identity, in that sociocultural processes related to race, gender, sexual orientation, and other identities shape the ways in which PLWH experience HIV-related stigma. However, few studies examine the impact of intersecting identities on HIV-related stigma among PLWH. The studies that exist generally rely on restrictive demographic sampling frames to infer the impact of identity on stigma, rather than assessing participants' personal perspectives. The current study aims to begin to address this limitation. Twenty-one PLWH were interviewed about their experiences with HIV-related stigma and asked to describe how their identities impacted these experiences. Participants described ways in which intersections of multiple forms of discrimination such as heterosexism, racism, and sexism interact to shape experiences of HIV-related stigma and reinforce systems of marginalization. The findings of this study reflect the dynamic relationships between identity and broader social processes which serve to shape not only stigma experiences among PLWH, but also more expansive social disparities in power and well-being.

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## CHAPTER 1: INTRODUCTION, RATIONALE, AND PURPOSE

### Introduction

Human Immunodeficiency Virus (HIV) is a disease that impairs the body's immune functioning by destroying CD4 immune cells, making the body more susceptible to a number of opportunistic infections, which may lead to Acquired Immune Deficiency Syndrome (AIDS). HIV affects over 30 million people worldwide, with over one million people in the United States living with the disease (Centers for Disease Control (CDC), 2012; UNAIDS, 2007). While many strides have been made to successfully reduce the spread of HIV and advances in the treatment of the disease continue, HIV-related stigma remains among the greatest barriers to combating the disease effectively (AIDS Action, 2001; Herek, Capitanio, & Widaman, 2003; Valdiserri, 2002; World Health Organization, 2015).

HIV-related stigma refers to processes that discriminate against and discredit people living with HIV (PLWH) as well as the individuals and groups associated with the disease, such as men who have sex with men (MSM) and injection drug users (IDU) (CDC, 2000; Herek & Capitanio, 1999; Schellenberg & Bem, 1998). Stigma is, therefore, a social process that includes labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001). In this way, stigma is constructed within a social context at the intersection of power, culture, and difference (Parker & Aggleton, 2003) and maintains social inequality by granting power to the non-stigmatized and punishing



or blaming those that are stigmatized for possessing the devalued attribute. Stigma processes result in several outcomes for PLWH, including loss of income and livelihood, reduced access to (or quality of) health care, loss of social supports, and negative mental health outcomes (Ogden & Nyblade, 2005).

Various beliefs contribute to HIV-related stigma, including misinformation about the disease and moralization of behaviors and identities associated with the disease. Stigma around HIV generally includes one or more of the following: fear of contagion, associating HIV with death, disapproval of behaviors associated with HIV, taboos around sex, and a sense that HIV is punishment for personal irresponsibility or immorality. Although overt expressions of HIV-related stigma seem to have been reduced, largely due to increased HIV education efforts, many people continue to experience fear and prejudice toward PLWH (Valdiserri, 2002). While HIV-related stigma is recognized as a continuing barrier to optimal HIV prevention and care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Venable, Carey, Blair, & Littlewood, 2006), there is a dearth of recent empirical research examining the process and its impact. As most of the existing literature is over a decade old, current information is needed to understand how HIV-related stigma is enacted and experienced within the modern sociocultural environment. It has been 35 years since the epidemic arose within the United States and much has changed in the way both PLWH and the general public view the disease. Accordingly, the proposed project is designed to provide relevant information regarding the contemporary experiences of stigma among PLWH.

HIV-related stigma impacts PLWH through several processes, including overt expressions of discrimination and fear as well as less explicit messages through behavior, public policy, and social norms. Stigma expressions are often experienced as ubiquitous and diverse, making it difficult for PLWH to ignore and be unaffected by these messages. PLWH may internalize discriminatory societal messages toward HIV, beginning to endorse these negative views about themselves. Even if PLWH are resilient enough to protect themselves from internalizing these harmful messages, the stigma associated with their positive status is likely to impact their relationships, employment, access to treatment, and psychological well-being on some level. Stigma is further complicated by its dependence on multiple aspects of one's actual or perceived identity such as ethnic status, gender, and sexual orientation (Logie, James, Tharao, & Loutfy, 2011). HIV-related stigma intersects with other types of discrimination ("isms") in a way that complicates and compounds the experiences of stigma for PLWH. These factors greatly impact the ways in which PLWH are perceived and judged, with issues of intersectionality placing the individual at greater risk for experiencing discrimination (Earnshaw, Bogart, Dovidio, & Williams, 2013; King, 1988). For example, PLWH often report experiencing stigma beyond that based on their ethnicity (Logie, James, Tharao, & Loutfy, 2011) and evidence suggests that different combinations of stigmatized identities result in a diverse range of experiences (Purdie-Vaughns & Eibach, 2008).

A holistic conceptualization of HIV-related stigma requires an understanding of how social processes influenced by culture and structures of power and privilege shape PLWH's experiences. The experience of HIV-related stigma depends on intersectionality of identities, in that ethnicity, gender, sexual orientation, and other identity statuses

influence the way in which PLWH experience and internalize stigma. Furthermore, these multiple identity statuses may contribute to a relative position of disempowerment through societal processes which devalue a specific trait or group membership, further compounding the factors that shape HIV risk, treatment, and stigma. Thus, the experience of stigma is contingent on not just one aspect of identity, but an individual's identity as a whole. Multiple stigmas, including marginal-group member status and being HIV-positive, impact the experience a PLWH has with HIV-related stigma (Earnshaw & Kalichman, 2013).

### Rationale and Purpose

The current literature examining the impact of identity on the experience of HIV-related stigma highlights several considerations relevant to the present study. Firstly, most studies exploring the role of identity in the experience of HIV-related stigma examine one identity component at a time. Because intersectionality is complicated and difficult to measure and glean clear outcomes from, most studies choose to focus on a very limited number of components. While this approach makes sense in regard to clarity in methodology and measurement, it also limits the extent to which identity and stigma are conceptualized as the complex and interactive concepts that they are. Furthermore, the vast majority of existing research examines the impact of identity on stigma by controlling the identity components of the study population, rather than asking participants to describe how they identify themselves and how these identities impact their experiences. For example, studies looking at ethnicity, gender, and HIV-related stigma may only recruit Black men living with HIV and then ask questions about how these participants experience HIV, rather than have participants comment on their own

“Blackness” and “maleness.” In other words, the impact of race and gender is assumed via participant demographics in that only Black men are being recruited, rather than directly asking participants to describe in their own words how their identities shape experiences with HIV-related stigma.

In order to address these gaps in the existing literature, the present study utilized qualitative research methods established in an abductive approach (Locke, 2007; Timmermans & Tavory, 2012) using grounded theory methodology (Charmaz, 2006) to capture narratives from PLWHA and explore how intersecting identities shape experiences of HIV-related stigma. Rather than seeking to fit participants’ experiences into existing theory, this study aimed to allow participants to be experts of their own experiences with the intention of looking for surprising or novel data that facilitates development of new or more complete theory. In capturing participants’ narratives, the researcher considered the following research questions:

1. Which identity constructs are most salient in impacting PLWH’s experiences with HIV-related stigma?
2. How do identity constructs intersect and impact PLWH’s experiences of HIV-related stigma?

The use of a qualitative abductive approach highlights the impact of the researcher’s positionality and theoretical lens on both the participant and interpretation of the data. Because of the high potential for bias, it is imperative for qualitative researchers to be intentional and mindful about how data collection and coding are approached. Reflexivity, or awareness and interpretation of one’s own experiences, reactions, assumptions, and effect on the research process, is of utmost importance in ensuring

study quality and integrity. As such, it was necessary to follow established guidelines for examining the impact of my own bias throughout the data collection and analysis procedures. Further details about these specific procedures are included in Chapter 3: Study Methods. For an examination on how these biases and concerns may have impacted the study results, please see Chapter 5: Discussion.

## CHAPTER 2: LITERATURE

The existing literature offers two potential explanations of the ways in which multiple identities impact the HIV-stigma experience: layered or compound stigma (Earnshaw & Chaudoir, 2009; Nyblade, 2006) and intersectional stigma (Berger, 2004; Crenshaw, 1994). Layered stigma is an additive model which suggests that multiple stigmas uniquely contribute to the experience of stigma (Earnshaw & Kalichman, 2013). From this perspective, the amount of stigma experienced within each identity is measured and then summed to obtain the total amount of stigma experienced. However, it is argued by the author that this approach is limited in its assumption that individual identities can be singled out and examined distinctly. An intersectional approach offers an alternative, in that the model considers identities as interactive and interdependent (Berger, 2004). While this model acknowledges that stigmatized identities may be singled out and considered separately, it asserts that considering how these identities interact to shape stigma experiences provides a much deeper understanding of their impact on PLWH. As such, the proposed study serves to explore the relationship between intersecting identities of PLWH and their experiences of HIV-related stigma.

### Defining and Conceptualizing Stigma

The stigmatizing process is made up of labeling, discrediting, and “othering” (Link & Phelan, 2006; Maluwa, Aggleton, & Parker, 2002) and can be conceptualized at both cultural and individual levels (Herek & Capitanio, 1998). HIV-related stigma,

therefore, has multiple components that are often difficult to clearly distinguish. For example, at a structural and cultural level, HIV-related stigma is reflected in public and health policy, public discourse, and the social and economic conditions of PLWH and those at risk for infection (Herek & Capitanio, 1998). At an individual level, stigma is expressed through behaviors, cognitions, and affective responses that reflect negative judgment toward PLWH. Surveys indicate that approximately 20% of the general population endorse feelings of fear and disgust toward PLWH (CDC, 2000) and that many would choose to avoid individuals whom they know to be HIV positive (Herek, Capitanio, & Widamen, 2003). Supporting these findings, over 40% of PLWH endorse experiencing adverse reactions from others after disclosure of their positive status (Vanable, Carey, Blaire, & Littlewood, 2006). Because stigma is a dynamic and relational construct, it must be understood and conceptualized at multiple levels, including cultural/structural, interpersonal, and intrapersonal. HIV has great potential for stimulating multidimensional stigmatization for several reasons. These include beliefs that the disease is associated with deviant behavior, viewed as being the victim's fault, associated with immorality, perceived as highly contagious and dangerous, and is not well understood by society and negatively viewed by health care providers (Alonzo & Reynolds, 1995). Furthermore, the conditions of structural and institutional sexism and racism serve to perpetuate social conditions that are associated with increased risk of HIV infection (Sumartojo, 2000).

#### Sources of HIV-Related Stigma

HIV-related stigma impacts PLWH through the impact of the reactions of others toward PLWH (Earnshaw & Chaudoir, 2009). For those with a seronegative status, these

reactions may include prejudice, stereotypes, and discrimination that lead to social distancing and influence views toward policy associated with HIV (Earnshaw & Chaudoir, 2009). For those who are infected, these mechanisms are experienced as enacted, internalized, and anticipated stigma. Enacted stigma represents the level of prejudice and discrimination PLWH believe they have experienced based on their positive status (Scambler & Hopkins, 1986). Internalized stigma reflects the level to which PLWH endorse the negative beliefs and feelings associated with HIV about themselves (Link, 1987), while anticipated stigma is the expectation of experiencing prejudice and discrimination from others in the future or as a result of disclosing a positive HIV status (Markowitz, 1998).

Data indicate that a significant portion of the American public endorses beliefs and feelings that reflect HIV-related stigma (Herek & Capitanio, 1998; Valdiserri, 2002), and that these negative reactions generally stem from two sources, instrumental and symbolic stigma (Herek & Capitanio, 1998). The first, instrumental stigma, is defined by a fear of HIV, either related to contagion or viewing the disease as a death sentence (Herek & Capitanio, 1998). Instrumental stigma also encompasses the belief that PLWH are less competent or less able to contribute because they are HIV-positive. Instrumental stigma is generally rooted in misinformation about HIV transmission, prognosis, and symptoms. The second, symbolic stigma, refers to social evaluative meanings associated with the disease (Herek & Capitanio, 1998). Many of the risk behaviors associated with HIV are moralized on a social and cultural level, including MSM, IDU, multiple sex partners, and sex work, which can contribute to beliefs that PLWH somehow “deserve” contracting the disease because they “violated” a socially constructed idea of morality.



While fear of transmission and the belief that HIV is a death sentence would be considered instrumental stigma, the labeling of behaviors associated with HIV risk (i.e., IDU or MSM) as moral misconduct or “dirty” would be an example of symbolic stigma. Among a sample of heterosexual adults in the United States, 41% endorsed symbolic stigma, 13% endorsed instrumental, and 30% endorsed both (Herek & Capitanio, 1998). The authors note that these data reflect the importance of considering instrumental and symbolic stigma separately, rather than considering them opposite ends of a single dimension.

### Instrumental Stigma

HIV, like other diseases with uncertain prognoses and no cure, has elicited fear since the beginning of the epidemic (Sontag, 1991). HIV is widely seen as a permanent, deteriorating, and fatal condition that is contagious, which may elicit avoidance behavior and fear among those who are seronegative (CDC, 2000). Further contributing to fear surrounding HIV are myths about transmission (Herek & Capitanio, 1994; Herek & Capitanio, 1997; Herek & Glunt, 1991; Piot, Kazatchkine, Dybul, & Lob-Levyt, 2009; Price & Hsu, 1992; Stipp & Kerr, 1989). However, there is a lack of research examining instrumental stigma directly and so, for the purposes of this literature review, the literature examining misinformation about HIV transmission was examined as a proxy for instrumental stigma. There is a lack of recent studies examining the current state of HIV misinformation in the United States and the data that does exist is over a decade old. These studies indicate that, at the turn of the century, a significant proportion of society held inaccurate beliefs regarding the transmission of HIV. For example, 40% of a sample endorsed the belief that HIV transmission is possible through sharing a glass or by being

coughed or sneezed on by a PLWH (CDC, 2000). A more recent survey found that a significant percentage of Americans believe HIV can be transmitted through kissing (37%), sharing a glass, (22%) or touching a toilet seat (16%) (Kaiser Family Foundation, 2006). Furthermore, even among young adults enrolled in biology courses, a significant portion were found to reflect a naïve or intermediate understanding of HIV, characterized by endorsement of HIV myths such as believing that the risk of becoming HIV-positive can be minimized by expelling the virus from your body through fluids and that contracting other sexually transmitted diseases reduces the risk of contracting HIV (Keselman, Kaufman, & Patel, 2004). There is surprising lack of research examining the relationship between HIV misinformation and HIV-specific stigma; therefore, while it seems logical that misinformation would contribute to stigma, there is little data to inform the existence or nature of the possible association. While lower HIV knowledge has been found to be associated with higher stigma scores among Chinese HIV positive children (Zhao et al, 2011) and reduced willingness to disclose positive status among rural to urban migrants in China (Yang et al., 2006), there is a lack of studies done in the United States that focus on the relationship between HIV knowledge and HIV-specific stigma beliefs among seronegative individuals.

### Symbolic Stigma

Symbolic stigma is enacted on the individual level and is shaped by broader cultural norms and values. The symbolic, or morally-based, stigma associated with HIV is rooted in sociocultural definitions of morality and may serve to distance the individual from the fear of infection by enabling denial of their own risk (Stein, 2003). In other words, symbolic stigma could be understood as the idea that “bad” things only happen to

“bad” and deserving people. Symbolic stigma is also used as a method of maintaining social order and control by marginalizing and excluding those who display undesirable traits or engage in behavior deemed “immoral” (Aggleton, 2000). Therefore, moral stigma associated with HIV serves to reinforce more conventional social norms surrounding fidelity, family, sexual behaviors, and substance use. These moral judgments are rooted in both religious and social values, in that it is argued that promiscuity and same-sex sexual activity, which are factors in HIV risk, lead to a breakdown in social and family cohesion (Stein, 2003). For example, data indicate that a significant proportion of the American population considers same-sex relationships (Avery et al., 2007; Craig, Martinez, & Kane, 2005) and sexual promiscuity among women (Valenti, 2010) as immoral and threatening to traditional values.

The symbolic components of HIV-related stigma are rooted in the association between HIV and the attitudes people have toward at-risk groups and the behaviors that they engage in that increase transmission risk, such as MSM and IDU. For example, anti-gay beliefs have been found to be strongly correlated with reduced HIV knowledge and higher levels of HIV-related stigma (Carney, Werth, & Emanuelson, 1994; Price & Hsu, 1992; Royse & Birge, 1987). Illustrating the impact of this relationship, a survey conducted at the turn of the century indicated that 19% of respondents believed that a healthy man could get AIDS if he had sex with an uninfected man, even if they used condoms (Herek & Capitanio, 1999). If the uninfected couple was to have sex without condoms, 47% of the sample believed that HIV transmission was possible. In other words, almost half of the Americans interviewed thought that gay men, just by being gay, transmit HIV, even if they are not infected. Unfavorable opinions toward other

stigmatized groups, such as IDUs or commercial sex workers, are also related to HIV-related stigma (Capitanio & Herek, 1999; Scambler & Paoli, 2008; Semple, Patterson, & Grant, 2004). At the turn of the century, data indicate that approximately 20% of Americans believe that those who have been infected with HIV through sex or drug use deserve it (Herek, Capitanio, & Widamen, 2002). As previously described, stigma associated with drug use and commercial sex work has the potential to influence public policy decisions regarding HIV prevention programs, such as access to harm reduction materials.

### Stigma and Ecological Systems Theory

In order to better conceptualize the dynamic and complex factors contributing to the development, experience of, and perpetuation of HIV-related stigma, it is helpful to structure this process within an ecological model. Ecological models provide a framework from which to understand the conditions and processes that shape the course of human development within environmental contexts (Bronfenbrenner, 1994). One such framework, the bioecological model (Bronfenbrenner, 1995), is based on the following propositions: (1) Human development occurs through processes of increasingly complex reciprocal interactions between the ever-evolving biopsychological individual and the other people and entities in their immediate surroundings and (2) these processes vary as a function of the individual's characteristics, the environmental context, and the nature of the developmental outcomes being considered. Within this model, the ecological environment is viewed as a set of nested layers (individual, microsystem, mesosystem, exosystem, and macrosystem), existing within one another (Bronfenbrenner, 1994). Within this model, HIV-related stigma can be understood as perpetuated through and by

the dynamic interactions between the individual, the people they engage with (e.g., family, friends, medical providers), social institutions and structures (e.g., religion, justice systems, education), and culture (e.g., morality, racism, sexism, media).

#### Individual Level and Stigma Processes

Every individual exists within a unique ecological context, with a variety of factors influencing their values, behaviors, beliefs, and experiences. From the ecological systems perspective, the environment not only impacts the individual, but also the individual exerts power and influence on their environment and associated processes. Individual characteristics, such as age, gender, sexual orientation, race/ethnicity, and health status serve to influence other factors, and their interactions, at multiple levels. Within the contexts of HIV, stigma impacts the internal experiences of PLWH in the form of emotions, self-beliefs, and ability to cope. Isolation (imposed by self or others) and experiences of discrimination may lead to the disempowerment of PLWH and individuals within at-risk groups. Processes of disempowerment first exist as interactions between those that are marginalized and others, including messages that the PLWH is to blame, deserves HIV as a punishment, or should be avoided. These interactions can result in external consequences, such as reduced support, access to care, and prejudice, as well as an internalized lack of self-efficacy or self-worth (Herek, 1990; Lee, Kochman, & Sikkema, 2002; Lewis, 1998; Novick, 1997). Simply put, experiences of discrimination impact the emotions, thoughts, and behaviors of the individual, which in turn impact how the individual interacts with others. Supporting this assertion is extensive evidence that finds a significant associations between stigma experiences and higher rates of psychological distress among PLWH (Sayles, Wong, Kinsler, Martins, & Cunningham,

2009; Vanable, Carey, Blair, & Littlewood, 2006; Ware, Wyatt, & Tugenberg, 2006; Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009).

A major proposition of the ecological systems theory is that the multiple system layers dynamically interact; therefore, in order to understand the individual emotional, cognitive, and behavioral consequences of stigma, it is necessary to consider the influences of the other layers on the individual. For example, revealing one's positive status puts an individual at risk for discrimination, alienation, and the potential revelation of other aspects of one's identity that could further stigmatize them within relationships and a broader cultural context (e.g., disclosure of sexual orientation or substance use). Therefore, in order to avoid discrimination, PLWH may choose to conceal their status from others. While maintaining confidentiality regarding disease status may reduce some negative interpersonal consequences, the lack of transparency may result in anxiety related to the stress of continually managing information regarding their stigmatized status (Hays et al., 1993). The ambiguity of these social interactions may lead to increased distress due to the threat of possible discovery (Pachankis, 2007). Unlike those with an obvious and visible trait associated with stigma, many PLWH must face disclosure decisions with every new encounter in determining whether to communicate their serostatus (Chesney & Smith, 1999; Crandall & Coleman, 1992; Parsons, VanOra, Missildine, Purcell, & Gómez, 2004; Simoni et al., 1995). Concealment of one's status can lead to social isolation and lack of support, but may also emerge as a barrier to seeking treatment, maintaining adherence to medication regimens, and obtaining psychosocial services (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Sayles, Wong, Kinsler, Martins, &

Cunningham, 2009; Vanable, Carey, Blair, & Littlewood, 2006). As such, an individual's willingness to disclosure and seek support will be largely dependent on structures, and the interactions between structures, at all levels of the ecological system.

#### Microsystem Level and Stigma Processes

The microsystem contains the structures with which the individual has direct contact and encompasses the relationships and interactions an individual has with their immediate surroundings (Berk, 2000). Structures in the microsystem include, but are not limited to, family, health care professionals, neighborhood, and employment environments. These relationships occur bi-directionally, both away and toward the individual. For example, an individual's family will impact the behavior and beliefs of the individual, but the individual also impacts the behavior and beliefs of the family. For example, family beliefs regarding same-sex relationships will likely have a significant impact on disclosure decisions of an individual who identifies as gay. Relatedly, having a family member "come out" as gay has the power to shift family values and beliefs about same-sex relationships. Through these sorts of interpersonal processes, stigma shapes the risk and health behaviors of PLWH. For example, fears of judgment and stigmatizing responses have been identified as barriers to speaking with health providers about sex behaviors (Cunningham, Tschann, Gurvey, Fortenberry, & Ellen, 2002; Makadon & Silin, 1995) and sex without disclosure of one's status (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009). Fear of HIV-related stigma also reduces willingness to be tested and to seek information regarding risk reduction (Chesney & Smith, 1999; Fortenberry et al., 2002; Myers, Orr, Locker, & Jackson, 1993; Stall et al., 1996). Stigma has been found to

interfere with medication adherence and access to medical care among PLWH (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Venable et al., 2006; Wolitski et al., 2009) and has been found to exist within both health care provider relationships (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007) and personal relationships (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Ware, Wyatt, & Tugenberg, 2006). As these studies indicate, delays in testing, as well as hesitance in discussing risk reduction behavior with physicians, sex partners, or needle-sharing partners, have been found to be partially due to fear of adverse responses rooted in stigma.

#### Mesosystem Level and Stigma Processes

The mesosystem provides the connection between the structures of the individual's microsystem (Berk, 2000). This would include the relationships between an individual's family and peers, or the connection between their church and neighborhood. In other words, the mesosystem refers to the interactions between two or more microsystems. The negotiation of HIV-related stigma among different microsystems can be complicated for PLWH in that some microsystems may be deemed as affirming while others are not. However, since these microsystems exist simultaneously, they are likely to interact and influence one another, making it difficult to compartmentalize the dynamics of one from another. For example, a person who is HIV positive may find great value and support in participating in HIV advocacy; however, if their role as an advocate and "out" PLWH is made public to their peers and family, this could create conflict if the PLWH's family prefers that the individual's status remain undisclosed or are unaware of the individual's status.



### Exosystem Level and Stigma Processes

The exosystem defines the larger social system, such as media and local politics, in which the individual does not function directly. The structures in this layer impact the individual's development by interacting with other structures within microsystem (Berk, 2000). Media messages addressing the HIV epidemic and prevention or community-based resources are examples. The individual is not directly involved at this level, but is impacted by the exosystem's impact on more immediate structures such as family values and government sponsored education.

Within the exosystem, stigma exists at a structural and cultural level, manifesting as policies that discriminate against PLWH. HIV has been stigmatized in the United States since the beginning of the epidemic, as is evident in public attitudes and practices toward PLWH and at-risk groups (Herek & Capitanio, 1998). Politically, HIV-related stigma has hindered the public health response to the disease by shaping the development of legislation preventing the provision of explicit risk reduction information to at-risk groups (Chillag et al., 2002; Gaiter & Doll, 1996) and federal opposition to harm reduction efforts such as needle exchange programs (Des Jarlais, 2000; Taussig, Weinstein, Burris, & Jones, 2000), despite the evidence supporting the effectiveness of these efforts in reducing HIV transmission (Drucker, Lurie, Wodakt, & Alcabes, 1998). Early conversations regarding options for addressing the HIV epidemic included mandatory quarantine and identifying tattoos (Frieden, Das Douglas, Kellerman, & Henning, 2005). Within the United States, a third of the population endorsed quarantine in the early 1990s, but by 1997, this number dropped to one in six due to education efforts aimed at dispelling myths about HIV and its transmission (Herek, Capitanio, &

Widaman, 2003). Other examples of HIV discrimination at a structural level are evident in the experiences of PLWH and accessibility of resources, in that a significant proportion of PLWH report having their positive status limit employment and housing opportunities as well as serving as a barrier to health care services due to HIV-related stigma (Kass et al., 1994; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Rao, Angell, Lam, & Corrigan, 2008).

#### Macrosystem Level and Stigma Processes

The Macrosystem level is comprised of cultural norms, values, and laws (Berk, 2000). These overarching principles progressively influence the interactions between all of the other layers. For example, PLWH may be at risk for experiencing stigma based on individual characteristics such as sexual orientation or history of drug use, the meaning of which are shaped by cultural beliefs at the Macrosystem that frame same-sex relations and illicit substance use as deviant or immoral. For example, if the broad cultural belief is that those who have acquired HIV through sexual contact or drug use deserve it, then society is less likely to provide resources to reduce infection through these methods (e.g., harm reduction). In this manner, cultural beliefs shape the structures in which individuals function.

The perpetration of stigma is highly motivated by moral values and enacted within social and cultural processes throughout the layers of the social ecosystem (Asiedu, 2007) as macrosystem structures shape individual feelings of discomfort and isolation (individual), likelihood of violence or discrimination (microsystem), perceived support (mesosystem), and access to health care resources (exosystem). When stigma is rooted in moral values, it exerts its effects by threatening or diminishing core values

across ecological systems in the form of cultural meanings, affective states, roles, and schemas of ideals (Yang et al., 2007). Therefore, stigma based beliefs can be conceptualized as a reflex emerging as an act of self-preservation and psychological defense against larger internalized cultural norms of sanctity (Yang et al., 2007).

The existing data support the role of macrosystem level influences in impacting individual views toward PLWH. For example, negative views of PLWH and groups at risk for infection (e.g., MSM and IDU) are associated with stronger support for health policy that is related to discrimination, such as quarantine and name-based surveillance (Herek, Capitanio, & Widamen, 2002). Furthermore, negative attitudes toward PLWH, manifested as negative evaluations and discriminatory behavior, exist not only among the general public (CDC, 2000; Herek, Capitanio, & Widamen, 2002), but also health care professionals (Rintamaki, Scott, Kosenko, & Jensen, 2007; Weiss & Ramakrishna, 2001). These data reflect the larger cultural zeitgeist of framing HIV as a dangerous disease rooted in moral evaluations.

As the literature indicates, HIV-related stigma exists within a variety of contexts and across layers of the ecological system. The evidence further indicates that these stigma processes impact PLWH and at-risk groups in a myriad of ways, hindering efforts aimed at reducing transmission and improving the welfare of PLWH. While a greater understanding of HIV-related stigma processes is useful in guiding these efforts, focusing on stigma associated with HIV alone is not sufficient in adequately capturing and explaining the experiences of PLWH. Individuals living with the disease are also defined (by self and others) by many other aspects of their identity beyond their disease status, such as their gender, sexual identity, race/ethnicity, and other identities. These

intersections of identity serve to shape and define not only the way others see and behave toward PLWH, but also how PLWH see themselves. The stigma associated with other marginalized identities (such as heterosexism, racism, and sexism) interacts across socioecological levels as well, perpetuating the disparities in privilege that serve to support a social environment that contributes to HIV transmission and barriers to effective care.

### HIV and Identity: Issues of Intersecting Stigma

As stigma is a social process that is formed and perpetuated by social disparities (Castro & Farmer, 2005; Link & Phelan, 2001; Parker & Aggleton, 2003), stigma exists beyond issues related to the disease itself (e.g., curability and transmission) and is shaped by the identity of those affected. The experience of HIV-related stigma further marginalizes groups that are already diminished based on attributes such as race, gender, sexual orientation, drug use, or socioeconomic status (Nyblade, 2006; Reidpath & Chan, 2005). For instance, among PLWH, higher internalized stigma scores are related to being a racial minority, low levels of education, not being a native English speaker, and heterosexual orientation (Sayles et al., 2008). Higher internalized stigma scores among heterosexual participants could reflect differences in social contexts. In other words, the gay male community was the first and hardest to be hit by the HIV epidemic and there is a long history of activism and education within the community which may mitigate the stigma experienced among gay men.

Overall, the evidence indicates that HIV disproportionately affects minority groups. For instance, in 2010, 44% of all HIV cases in the United States were accounted for by Black people, an infection risk eight times that of White people (CDC, 2014a).

Although men currently have higher HIV rates than women due to higher rates of MSM transmission (CDC, 2008), trends in infection indicate that Black heterosexual women are the fourth largest group of new infections (CDC, 2014a). As the proceeding literature review aims to clarify, minority groups are not only at disproportionately greater risk of HIV infection, but are also more likely to experience stigma related to HIV. As recommended by Stein (2003), because HIV disproportionately affects those from minority groups it is useful to examine the relationship between HIV-related stigma and other forms of discrimination such as race/ethnicity, gender, and sexual identity; allowing for a comparison between HIV-related stigma and other measures of social prejudice and levels of bigotry across multiple contexts.

HIV-related stigma is complicated by the intersection of social stigma related to other aspects of identity, such as sexual orientation, gender and race or ethnicity. These stigma processes interact across socioecological levels (individual, micro, meso, exo, and macro), just as stigma related to HIV itself does. In fact, these pre-existing stigmas, and the disparities in power and privilege they perpetuate, are an inherent part of the HIV epidemic in that they create social circumstances that foster HIV transmission and maintain barriers to care. For example, because illicit substance use is illegal and largely moralized, it was feared that harm reduction efforts aimed at reducing the spread of disease (e.g., needle exchange) would increase drug use or be seen as an act of condoning illegal activity (Anderson, 1991; Vlahov et al., 2001). Similarly, anti-gay beliefs lead to reduced support for comprehensive sex education (Santelli et al., 2006) and internalized anti-gay beliefs among MSM are associated with increased HIV risk behavior, such as

unprotected sex and sex with multiple partners (Nicholson & Long, 1990; Stokes & Peterson, 1998).

In this way, PLWH may be stigmatized not only because of their serostatus, but also based on ethnicity, sexual orientation, gender, substance use, and other aspects of their identities (Parker & Aggleton, 2003). Stigmatization occurs within the framework of complex systems of multiple identities and oppressions, with systems of power that perpetuate disparities based on the alignment of race, class, gender, and sexuality (Collins, 1999; Crenshaw, 1994; Stewart & McDermott, 2004). These distinct, but interlocking, forms of stigma shape the social construction of the disease, access to care, policy, and the manner in which HIV-related stigma is manifested across all ecological systems. Therefore, other stigmas may interact with HIV-related stigma, resulting in variability in how the general population and care providers respond to PLWH (Mahajan et al., 2008; Novick, 1997).

While considerable data exist to support the impact of HIV-stigma, sexism, racism, and anti-gay beliefs on the health outcomes of PLWH, there is very little information or focus on how these forms of stigma interact. One way to conceptualize how multiple stigmas impact the experience of HIV-stigma is through an intersectional lens, which acknowledges the inseparability of identity categories while recognizing the heterogeneity of various groups (Simien, 2007). The term intersectionality in regard to identity was first used by Crenshaw (1989) to describe the multidimensionality of the experiences of marginalized individuals. The framework of intersectionality maintains that identity categories such as gender, race, ethnicity, class, and sexuality are mutually constituted, cannot be added together, and are social processes (Collins, 2000). Existing

research has utilized intersectionality as an analytic and theoretical frame to elucidate the complexities of oppression, allowing for a more nuanced understanding of identities within varying contexts (Syed, 2010). However, intersectionality can be understood as more than an analytical tool for understanding structural oppression as it also includes the process by which individuals become aware of the role of intersecting identities within their own lives (Syed, 2010).

A useful resource in understanding how intersecting identities impact the experiences of stigma and oppression is offered by Purdie-Vaughns and Eibach (2008), who have developed a model of intersectional invisibility. Intersectional invisibility refers to the process of being rendered “invisible” due to multiple subordinate-group identities which define the individual as non-prototypic within a respective identity group. The authors describe how the tendency to define the standard person as male (androcentrism), White (ethnocentrism), and heterosexual (heterocentrism) may lead to individuals who have intersecting identities to be seen as non-prototypical members of their constituent identity groups. For example, a Black woman may not feel her experience fits the more general group of “women,” and by ignoring her unique experience, important information is lost and the voice of Black women is ignored. Therefore, individuals who embody multiple stigmatized identities are at risk of being further marginalized within already marginalized groups. This invisibility, as the authors define it, may have both its advantages and disadvantages. For example, the authors describe how, by not fitting into the stereotype of a given marginalized group, non-prototypical members may elude active forms of oppression and discrimination. They cite evidence that racial stereotypes are more likely to be endorsed toward targets with more

stereotypically Black features (Blair, Judd, Sadler, & Jenkins, 2002; Eberhardt, Davies, Purdie-Vaughns, & Johnson, 2006; Eberhardt, Goff, Purdie-Vaughns, & Davies, 2004; Maddox, 2004) and that male same-sex relationships elicit a greater stigma than female same-sex relationships due to the dismissal of female sexuality within an androcentric society (Kite & Whitley, 1996; Bem, 1994). However, being non-prototypical also has its disadvantages in that individuals who embody multiple non-privileged identities often struggle to be represented and heard. For example, individuals with intersecting minority identities are less likely to hold a leadership position and exercise social influence within their respective groups (Hogg, 2001). These data reflect the import of considering how overlapping marginalized identities contribute to the unique experiences of those that hold them.

The concept of intersectional identities allows for an infinite number of identities to be considered; however, the existing literature on identity and HIV-related stigma examines the constructs of gender, sexual orientation, and ethnicity. Therefore, the subsequent literature review will center on these three constructs, mirroring existing exploratory research examining identity and HIV-related stigma which indicates that the gender, sexual orientation and ethnicity are often most salient for PLWH's experiences with stigma (Collins, von Unger, & Armbrister, 2008; Earnshaw & Kalichman, 2013; Logie, James, Tharao, & Loutfy, 2011).

Because stigma is experienced dynamically across systems and contexts, it is necessary to take into consideration issues of intersectionality in order to fully understand the perpetration and experience of HIV-related stigma. Several studies have utilized an intersectional theoretical approach to examine the layers of stigma experienced by



women living with HIV: findings indicate that intersections between racism, sexism, and heterosexism and anti-gay beliefs have a negative impact on health outcomes and psychosocial well-being of PLWH (Collins, Von Unger, Armbrister, 2008; Doyal, 2009; Logie, James, Tharao, & Loutfy, 2011). However, there remains a need for broader integration of intersectionality in HIV-related stigma research in order to develop a comprehensive conceptual model of HIV-stigma, including other marginalized identity constructs (Mahajan et al., 2008).

Research aimed at considering the meaning and consequences of multiple social group memberships has inherent difficulties. There are few established procedures for empirically addressing intersectionality research questions, which often leaves researchers feeling pressured to develop complex designs and recruit very large sample sizes in order to adequately address the complicated processes and variables inherent in intersectionality research (Cole, 2009). Cole describes the methodological challenges associated with intersectionality research, positing that such inquiries require a new perspective that considers the diversity within social categories, the uneven distribution of power and privilege across social categories, and searches for commonalities across social categories that are often considered as very different. Intersectionality research is therefore hindered by several methodological difficulties inherent in existing research. Cole describes these difficulties as a lack of measures developed from the perspective of the studied group, neglect of issues of power and privilege within differences research, a tendency to view social categories as individual characteristics rather than dynamic shared exchanges, and a general disregard of differences within labeled groups. While the proposed study does not address all of the implications inherent in conducting

intersectionality research, it does strive to consider the main tenets attached to the framework. Namely, to explore how multiple intersecting identities, within the social contexts of inequality and privilege, influence PLWH's experiences of HIV-related stigma.

#### HIV-Related Stigma and Race/Ethnicity

There is evidence to suggest that ethnicity and race impact HIV-related stigma and associated mechanisms. For example, Black respondents have been shown to be more supportive of policies that serve to separate PLWH, express a stronger desire to avoid PLWH, and to be more concerned about HIV transmission while White respondents indicate more negative feelings toward PLWH and a greater tendency to blame them for their illness (Herek & Capitanio, 1993). Furthermore, Black PLWH report more instances of discrimination from others while White respondents are more likely to report wanting to keep their status a secret due to fears of interpersonal rejection (Rao, Pryer, Gaddist, & Mayer, 2008). Another study examining racial differences in perceived stigma found that among older adults living with HIV, minority respondents reported significantly higher levels of HIV-stigma when compared to White respondents (Emlet, 2007). Asian and Pacific Islanders may also be at higher risk of experiencing HIV-related stigma as socio-cultural norms define many HIV-risk behaviors as immoral, with undocumented Asians reporting higher levels of social rejection, negative self-worth, and interpersonal rejection than documented Asians (Kang, Rapkin, Remien, Mellins, & Oh, 2005). Furthermore, evidence suggests that the effects of stigma among Asian and Pacific Islanders may have a long lasting impact on self-esteem and psychological distress (Kang, Rapkin, & DeAlmeida, 2006).

## Sexual Orientation and HIV-Related Stigma

Stigmatizing attitudes are also disproportionately held toward MSM (Crandall, Glor, & Britt, 1997; Herek & Capitanio, 1999) with PLWH blamed to a higher degree if they are gay (Schellenberg & Bem, 1998). For example, data from the early 1990s indicate that people with anti-gay attitudes are most rejecting of PLWH, regardless of mode of transmission, and are unlikely to change their beliefs after being presented with information and education on HIV (Pryor, Reeder, & McManus, 1991). Further supporting the influence of individual beliefs toward sexuality on HIV-related stigma, anti-gay beliefs among both undergraduates and psychologists have been found to be associated with HIV-related stigma beliefs (Trezza, 1994).

More recent evidence suggests that stigma is the predominant cause of psychological distress among MSM (Goldberg & Smith, 2011; Lewis, Derlega, Griffin, & Krowinski, 2003; Sandfort, Melendez, & Diaz, 2007) and gay/bisexual sexual orientation has been found to predict reports of enacted stigma experiences (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). HIV status has the potential to create division even within the MSM community, as non-positive MSM have been found to hold stigmatizing beliefs toward MSM who are positive (Courtenay-Quirk, Wolitski, Parsons, Gómez, & the Seropositive Urban Men's Study Team, 2006).

Minority PLWH who identify as MSM are faced with an even more complex stigma experience as it relates to sexual orientation, race, and HIV status with gay, lesbian, and bisexual ethnic minorities reporting a higher level of experienced stress than their White counterparts (Meyer, 2010). For instance, the expression of HIV-related stigma is strongly tied to the prevalence of anti-gay beliefs in minority communities

stemming from cultural norms and values. For example, being gay is commonly viewed as “sinful” and “unnatural” in that it clashes with expectations regarding race, gender roles, masculinity and sexual behavior within the Black community (Herek & Capitanio, 1995; Stokes & Peterson, 1998). Furthermore, being gay is often framed as a weakness and embarrassment among both Black and Latino communities (Díaz, 1998; Díaz, Ayala, Bein, Henne, & Marin, 2001). In particular, Hispanic and Black MSM often live in communities where gender and sexuality norms further stigmatize HIV-infection and same-sex experiences and/or sexual orientation (Díaz, Ayala, Bein, Henne, & Marin, 2001; Herek & Capitanio, 1995; Lewis, 2003; Stokes & Peterson, 1998; Ward, 2005). In an analysis of a comparison of HIV and MSM stigma among HIV-positive Latino and Black MSM, Latino MSM reported experiencing more stigma related to their HIV status while Black MSM reported experiencing more stigma related to their sexual orientation (Wohl et al., 2013). The authors note that these results may be due to a greater likelihood of Latino MSM to conceal their status from others and increased levels of social support among Black MSM. For example, social support from friends has been found to be associated with lower levels of HIV-stigma among Black MSM who are HIV-positive (Galvan, Davis, Banks, & Bing, 2008). Data also indicate that MSM stigma has been identified as a barrier to seeking treatment for a “perceived gay disease” (Wohl et al., 2013, p. 1463) among Latino HIV-positive men, but not Black respondents, and that Latino HIV positive men are also more likely to withhold disclosure of their sexual orientation and serostatus (Mason, Marks, Simoni, Ruiz, & Richardson, 1995), suggesting unique cultural influences regarding sexual norms between the groups. However, data suggest that the higher rates of HIV among Black MSM is due to higher

rates of sexually transmitted diseases (which facilitate HIV transmission) and later diagnosis of HIV (Millet, Peterson, Wolitski, & Stall, 2006), rather than risk behaviors (Millet, Flores, Peterson, & Bakeman, 2007), which suggests cultural barriers to testing. It should also be noted that positive identification with one's ethnic and sexual identity can act as protective factors with strong connection to ethnic identity and positive attitude toward gay/bisexual people associated with better adherence and fewer missed doctor's appointments (Harper, Fernandez, Bruce, Hosek, & Jacobs, 2013).

#### HIV-Related Stigma, Gender, and Sexuality

In 2010, 25% of all HIV cases were women (CDC, 2014b), and rates of HIV among women are increasing. This is partially because they are at higher risk of infection due to the exposure area of the vaginal wall and sexual coupling patterns of young women with older men (Lindegren, Hanson, Miller, Byers, & Onorato, 1994; National Women's Health Information Center, 2009; Pettifor et al., 2005), with adolescent females displaying a three to six times higher rate of HIV than males (Pettifor et al., 2005; Shisana & Davids, 2004).

Feminist research has shown that gender and sex are essential factors in understanding all aspects of HIV, from transmission and treatment to stigma experiences (Bredström, 2006), raising questions regarding patriarchal and sexist influences on medical research, policy, and safer sex negotiations (Bredström, 2006; Doyal, 1994). The effects of marginalization and gender power inequalities contribute to women's vulnerability to HIV in a variety of ways (Gatali & Archibald, 2004). For example, Kaspar (1989) argues that because women living with HIV encompass such a diverse group, they lack a commonality of experiences and social cohesion, such as those shared

by gay communities, leaving them isolated and without political power. This lack of power is evidenced by the exclusion of HIV-positive women from enrollment in past HIV drug studies and programs (Bunting, 1996).

Gender, sexuality, and social conditions also greatly impact structures of safer sex practices, as these factors embody social norms and conventions. For example, traditional heterosexual femininity is culturally represented as sexual ignorance, sexual passivity, and as responsible for male satisfaction (Holland, Ramazanoglu, Sharpe, & Thomson, 1998). In regards to sexuality, social guidelines concerning sexual behavior differ between men and women. Sexuality is more acceptable, or even revered, in men, but is often cast as a source of shame or devaluation for women. Within these macro level cultural conventions, a woman asking her partner to wear a condom risks her femininity by appearing too sexually dominant and knowledgeable. From this perspective, males are also impacted by masculinity norms in that male sexuality is framed as a powerful and instant force (Holloway, 1996) that would be interrupted and threatened by condom use (Holland et al., 1998). As male sexuality is often conceived as being reactionary and powerful, as evidenced in adages such as “men can’t help themselves”, women are often targeted as the audience for safer sex campaigns; therefore placing the responsibility for protection on women (Wilton, 1997). However, as women within heterosexual relationships are often placed in the position of less power, a paradox is created where women bear the burden of protecting themselves from HIV, but often do not have the power and ability to do so effectively. In interviews of men and women being tested for HIV, Merithew (1995) found that men spoke of their past sexual experience with pride, while women responded with fear and shame. This social double-standard has led to a

view of women as carriers of HIV virus in their role of mothers who infect their innocent children or as sex workers who transmit HIV to their customers who, in turn, infect their innocent wives (Caravano, 1991).

Wilton (1997) describes how HIV discourse is similarly shaped by sexual orientation in that there are differing expectations and norms for heterosexual men and women, gay men, and lesbians. For example, heterosexual men may attempt to distance themselves from HIV because the disease has been equated with gay men. In this way, heterosexual men defend their masculinity by avoiding topics or behaviors related to same-sex sex or HIV (e.g., wearing a condom). Wilton purposes that gay-identified men's condom use behavior may be less influenced by a need to defend their masculinity. Individuals who do not identify as part of a binary sexual orientation or gender, as well as people who identify as transgender, are largely ignored within the literature on HIV risk behavior and point to a serious limitation in current knowledge which should be addressed in ongoing explorations of HIV risk.

The impact of these gender and sexual norms is represented in data, which indicates that women report experiencing a greater burden of stigma and blame regarding responsibility for being seropositive. HIV-positive women are disproportionately of minority racial status and have experienced a variety of forms of oppression; they are often blamed and labeled as drug users, prostitutes, and carriers (Bunting, 1996). Female gender has been found to be associated with higher levels of perceived stigma among young PLWH (Swendeman et al., 2006) and a meta-analysis of studies examining stigma among women living with HIV indicates that seropositive women fear the negative effects of stigma across a multitude of contexts including relations with friends,

employers, their children, and partners (Sandelowski, Lambe, & Barroso, 2004). The findings also elucidate the fear HIV-positive women have of being met with rejection, discrimination and violence as a result of their positive status and reflect how stigma is internalized, with women reporting that they feel dirty, dangerous, and lacking value. Furthermore, the results of this meta-analysis indicate that the experience of stigma was intensified for women as compared to men, due to feelings of guilt in having the capacity to infect children and a tendency for others to attribute promiscuity or substance use as the means by which a woman was infected with the virus. In fact, HIV-positive women report experiencing overt stigma at the hands of health care providers in the form of disdain toward decisions to have children and recommendations that these women have abortions or become sterilized (Green, 1996; Ingram & Hutchinson, 1999; Lawless, Kippax, & Crawford, 1996; Wagner et al., 2010). A more recent study indicates that perceived stigma continues to be a barrier to health care among HIV-positive women (Carr & Gramling, 2004); however, a recent Ryan White needs assessment co-conducted by the author found that PLWH reported being satisfied with their HIV care provider, with no differences in gender found (Scheid & Lovato, 2013). Findings from the needs assessment indicated that, while PLWH had experienced stigma within non-HIV care settings, the vast majority were pleased with the care they received from their primary HIV care provider. Therefore, it may be prudent in future research to distinguish between HIV and non-HIV care provider experiences when exploring HIV-related stigma within health care environments.



## HIV-Related Stigma, Gender and Ethnicity

There is evidence to suggest that the interaction between gender and ethnicity has a significant impact on HIV risk and the way the disease is experienced. Minority women are disproportionately affected by HIV with Black and Hispanic women being diagnosed with new HIV at a rate of 20 and 4 times the rate of White women, respectively (CDC, 2013). Furthermore, minority women at high risk also report less concern about HIV risk than high risk White women and report more misinformation about HIV (Kalichman, Hunter, & Kelly, 1992). A study exploring how the intersection of mental health, gender, ethnicity, and sexuality impact HIV risk among Hispanic women found that the stigma related to mental illness left women with reduced self-efficacy and social standing, leading to diminished leverage in negotiating within sexual relationships which placed them at higher risk for HIV transmission (Collins, von Unger, & Armbrister, 2008).

The evidence also suggests that minority HIV-positive women are treated differently than White HIV-positive women. For example, White middle-class women have been found to mitigate stigma-based assumptions that they contracted the disease through IDU, promiscuous behavior, or prostitution (Grove, Kelly, & Liu, 1997; Sandelowski, Lambe, & Barroso, 2004). However, because White middle-class women are less likely to be associated with HIV, they may also be more likely to experience delayed diagnosis due to underestimation of risk (Grove, Kelly, & Liu, 1997). Furthermore, Black women living with HIV have been found to be significantly more likely to fear family rejection when compared to White women living with HIV in rural areas (Sowell et al., 1997). Among Latina women, those who speak English have been

found to disclose their positive status to more people (particularly family) than their Spanish-speaking counterparts (Simoni et al., 1995).

There is also evidence to indicate that minority status among women living with HIV fosters the ability to develop effective coping strategies in resisting the effects of stigma. For example, while Black women living with HIV have reported experiencing despair, social isolation, and disregard in response to their positive serostatus, they also describe ways they have enlisted support, redefined stigma as ignorance, and become advocates in order to mitigate the discrediting effects of stigma (Buseh & Stevens, 2007). Among Asian/Pacific Islander women, disclosure to health care providers and social networks resulted in support and personal growth (Chin & Kroesen, 1999). Therefore, while HIV-positive minority women face unique and considerable challenges regarding stigma, the evidence also suggests protective factors that may be related to ethnic and cultural identity.

#### Intersections Beyond Race, Gender, and Sexual Orientation

While the existing literature provides a basic framework from which to contextualize the experience of HIV-related stigma, there remain significant holes and limitations. Firstly, the existing literature largely relies on quantitative measures. While this approach supports the generalization of results and expedites the data collection and analysis process, there are also ways that this approach is limiting; particularly when the question at hand is intersectionality and personal identity. Identity is a matter of personal narrative and context; and thus by quantifying such an abstract variable, much of the meaning and context is lost. In fact, the voice of the participant is lost by reducing it to numbers, which may contribute to further disempower and silence those that already face

marginalization. Secondly, most of the existing HIV-related stigma and identity research examines the influence of distinct identities, rather than exploring the intersection of multiple identity factors. Logistically, this approach is practical and certainly provides meaningful information that is useful in guiding subsequent questions regarding the nuance of culture and identity in shaping stigma experiences; however, a person's experience is not compartmentalized by their identities. Rather, the human experience is the result of integrated identities that make up a whole person. Therefore, a more holistic and integrated view of how identity shapes HIV-related stigma, in the words of those affected, is largely missing from the existing picture.

A better understanding of the ways in which various identity components influence the experience of living with HIV is relevant for guiding education and intervention efforts aimed at reducing HIV-related stigma. Additionally, the impact of intersecting identities is pertinent in building successful psychosocial supports for PLWH as well as informing health promotion initiatives. An enhanced understanding of how different forms of stigma intersect may guide the identification of those individuals most at risk for experiencing stigma as well as identify cultural or identity components that are protective factors for PLWH. The research aim guiding the design of the proposed study is to develop a better understanding of how multiple intersecting identities of PLWH influence their experience of HIV-related stigma.

## CHAPTER 3: STUDY METHODS

### Research Design

The present study utilized a qualitative research design from an abductive approach (Timmermans & Tavory, 2012) and utilized grounded theory methods for analyzing the data (Bulawa, 2014). Grounded theory is a methodology widely used in qualitative research as a means of approaching a research question from a perspective of discovering theory, rather than one of testing theory (Rennie, 1998). However, as the researcher was familiar with the existing literature on HIV-related stigma and had worked in HIV advocacy for some time, there were limitations to the extent to which the data could be approached without preconceptions or assumptions. As such, the data was approached from the pre-existing theoretical frameworks of intersectional concept of identity, bioecological systems model, and social justice perspective. This approach is consistent with abductive analysis, which serves to produce novel hypotheses and theories based on identifying surprising data and findings that are incongruent with existing frameworks (Timmermans & Tavory, 2012). Therefore, a prior literature review guided the development of the semi-structured interview process while grounded theory concepts of open and axial coding, constant comparison method, and use of theoretical memos (Strauss & Corbin, 1998) were utilized to enhance theoretical sensitivity. This approach was chosen as a means of allowing participants to describe the personal ways in which they make sense of their own identities and experiences, providing for a more

complete and whole picture of how identity and HIV-related stigma are related. Furthermore, by focusing on qualitative data, rather than confining responses into predefined categories or response options, the data may better reflect the personal narratives of participants. This aspect was especially important to the researcher in coming from a social justice perspective, in that it was hoped the data collection process would be a practice in empowering PLWH as the experts of their own experiences. Although qualitative data are more difficult to generalize to broader populations and are subject to alternative interpretations, the approach remains a valid means of exploring lived experiences and meaning-making processes. As the constructs of interest, intersectionality of identity and HIV-related stigma, are complex and not easily quantifiable, it is argued that a qualitative method was best suited to capture the research questions at hand.

### Participants

Twenty-three people contacted the researcher with interest in the study; one was not HIV-positive and another potential participant did not want to participate due to the potential length of the interview. A total of 21 participants provided informed consent and completed the interview process. These 21 individuals were between the ages of 20 and 64 (mean age = 43.9 years, median age = 44 years) and had been living with HIV between 1 and 28 years (mean years = 14.1, median years = 15). All of the 12 men interviewed identified as men who have sex with men (MSM) and described their sexual orientation as gay. Ten of the men interviewed identified their racial identity as Black and two as White. All nine women who were interviewed identified as women who have sex with men (WSM) and identified their racial identity as Black. It should be noted that two

participants, one male and one female, indicated that they were multiracial (Puerto Rican/Black, Hispanic/Black, respectively); however, both described their ethnicity as Black. Therefore, for data analysis purposes, both participants' ethnicities were coded as Black. Given participants' identities, the themes, codes, and categories that arose from the data generally reflected the experiences of Black MSM and Black WSM. Participants reported having between 10 and 16 years of education (mean years of education = 13.48 years). Ten participants reported being unemployed and on disability, one reported having social security, one reported being retired, and nine participants reported either full- or part-time employment. All participants were currently receiving antiretroviral treatment and reported being connected with health care services. See Table 1 for a full detailing of demographic information and endorsed identity constructs. Interviews varied in length from 43 minutes and 106 minutes (combined interview time = 26 hours and 42 minutes; average interview time = 78.28 minutes; median time = 80 minutes).

## Procedure

### Theoretical Framework

The current study utilized an intersectionality framework in order to consider how multiple identities impact the experience PLWH have with HIV-related stigma. While intersectionality has long been used to frame theory in feminist and anti-racist scholarship, there remains little consensus on how to measure multiple subject positions (Nash, 2008). McCall (2005) describes three approaches to measuring identity constructs within intersectionality research. The first is referred to as anticategorical complexity and is based on the understanding that identity is too complex to be reduced into fixed categories. This approach is effective in capturing the complexity of social life, but also

rejects the use of categories as too simplistic, making the process of data collection more complex in turn. Another approach, intercategory complexity, asks that researchers utilize existing categories to explore the associations between identity, inequality, and social contexts. This approach acknowledges the existing relationships of inequality among social groups and looks to expose these relationships using preexisting categories. The third methodological approach, intracategory complexity, utilizes marginalized intersectional identities as an analytic beginning that serves to reveal the complexity of lived experiences through narrative. This approach acknowledges the dangers of categorization, but does not completely reject the categories of identity. Instead, multiple marginalized identities are used to demonstrate the inadequacy of unidimensional categorization. The methodology of this study will be based on both intra- and intercategory approaches, as intersectionality research often crosses the boundaries of the intersectionality methods continuum (McCall, 2005). As such, participant narratives will be coded by categories of identity and their associations with processes of social inequality such as racism, sexism, and heterosexism. The proposed study is relatively exploratory in nature, therefore, analytical categories will be utilized to provide consistency between subject interviews and to anchor exploratory analyses. However, these categories will be approached as a starting point in order to explore the complexity of lived subjects' identities.

This approach is consistent with Blumer's (1969) portrayal of sensitizing concepts within grounded theory, which serves to guide questioning and sensitize the researcher to ask specific questions about the topic of interest. There is a significant amount of literature describing the correlation between a number of identity analytical categories

(e.g., ethnicity, gender, sexual orientation, substance use status, socioeconomic status) and HIV-related stigma experiences. Therefore, the current study probed for not only explicit identity categories that reflected the existing research, but also provided open-ended questions that allowed for participants to identify any other identity categories they felt were salient, but were not explicitly asked about earlier. For example, participants identified a variety of additional salient identities beyond those explicitly asked about, including their roles as caregivers, advocates, and friends or partners. One participant spoke of his mental health issues and another described her country of origin and related culture. Several participants reiterated their wish to be seen beyond their HIV diagnosis as a full person.

The proposed study's framework is based on an abductive perspective for data collection and analysis (Timmermans & Tavory, 2012). An abductive approach supports the development of new hypotheses and theories by comparing data to existing theoretical frameworks and identifying data that is surprising or incongruent. Abduction is distinct from inductive and deductive reasoning, seeking a fit between observed data and explanations by constructing reasons from observed consequences. An abductive approach shares several values and methods with grounded theory, in that both look to the data to develop theory, rather than seeking to fit the data into existing logic. This is counter to other theories which are rooted in preconceived hypotheses and rely on predefined constructs (Chamberlain, 1999; Charmaz, 2006). An abductive approach is comprised of simultaneous data collection and analysis, constructing analytic codes and categories from data, making constant comparisons at each stage of analysis, utilization



of field notes, and the advancement of theory at each step of data collection and analysis (Charmaz, 2006; Timmermans & Tavory, 2012).

As the influence of intersectionality on the experience of HIV-related stigma among PLWH has little existing data to guide theory development, it was decided that an abductive approach would be appropriate given the exploratory nature of the study and need for greater clarity within existing theoretical frameworks. Furthermore, the consideration of how intersecting identities and the associated structures of power and privilege impact individuals' experiences requires that participant voices be made the priority in study development and data collection and analysis. Therefore, an abductive analysis utilizing grounded theory methods is an appropriate choice in that it emphasizes the importance of participant agency and subjective meaning throughout the research process and recognizes that the researcher-participant relationship is interactive in nature (Holguín Cuádriz & Uttal, 1999), while utilizing existing frameworks from which to understand the data and identify novel hypotheses and theory.

Although there is no existing comprehensive theory or model that describes how intersections of specific identities impact HIV-related stigma experiences, there are existing models and theories which describe how HIV-related stigma is enacted (Holzemer et al., 2006; Parker & Aggleton, 2003), including from an ecological systems model (Logie, James, Tharao, & Loutfy, 2011). Therefore, the literature provides enough data and defined constructs to develop a basic framework to guide exploration of the research question and it is hoped that the findings of this study serve to contribute to existing theories by identifying data that illuminates limitations of existing models and

suggests novel theories. In particular, this data was approached from the lenses of intersectionality, bioecological systems theory, and a social justice perspective.

Furthermore, the researcher acknowledges her bias in being well-informed of the existing literature on HIV-related stigma and her role as an advocate for PLWH. The constructs used in this study are based on the current literature and pulled from the conversations the researcher has had with PLWH regarding stigma. For this reason, issues of research bias are salient in the current study and multiple strategies were employed to acknowledge and minimize the possible effects. These consist of the use of reflective commentary, theoretical memos, and member checks (Montgomery & Bailey, 2007; Shenton, 2004). Qualitative data analysis software (NVivo) was also utilized in conjunction with manual coding, which has been shown to achieve optimal results in qualitative data analysis (Welsh, 2002).

#### Sampling and Data Collection

The proposed study was conducted in a region of the Southeastern United States, which included six counties receiving funding under Part A of the Ryan White Act. The Southeastern region accounts for 44 percent of PLWH within the United States and there are a higher number of new cases of HIV in the South as compared to the rest of the United States due to income inequality, poverty, and lower access to health care services (CDC, 2015a). The sample included PLWH who were 18 years of age or older and were fluent in English.

Participants were recruited from June 2015 through November 2015 (IRB protocol number 15-01-08) utilizing purposive and convenience sampling among non-profit organizations serving PLWH, health departments, treatment sites, and through

connections with stakeholders and health care providers. After receiving institutional review board approval, flyers (Appendix A) were posted in waiting rooms and care provider offices, as well as provided to case managers and health care providers for referral. In addition, several participants were recruited through snowball sampling. The flyers provided basic information about the study including the project's toll free number. Interested persons were asked to call the project's confidential number where a recorded greeting instructed them to either leave a message or to call back at another time in order to reach the interviewer in person. Participants were then contacted by the interviewer and assessed for study eligibility by gaining verbal confirmation that each participant was 18 years of age or older, HIV positive, and could speak and understand English. Once a convenient time to complete the interview was determined (in a private and quiet location), the participant was read the consent form and asked to provide verbal consent to participate (See Appendix D). Once the participant consented, they were interviewed via phone conversation and the interview was recorded using a digital voice recorder with an earphone style microphone. The process of obtaining verbal consent via phone is consistent with the method employed by Scheid & Lovato (2013) in conducting a Ryan White Needs Assessment of the same geographical area.

#### Data Management and Confidentiality

Participants were not asked to provide any personal identifying information and no personal identifying information was recorded. Instead, a numerical identification number based on the date and time of the interview was used to distinguish participant data. This identification number was never associated with identifying information. Verbal informed consent was obtained from all participants before being interviewed and

all interviews were audio recorded and transcribed. The data were stored on a secure computer using Microsoft Word. Data were password protected at several access points: computer log-in, folder access, and individual data file access. Only the principal investigator, her research advisor, and research assistant had access to the data. The audio-taped data were manually transcribed verbatim by the principal researcher as soon as possible, generally within 48 hours of recording, and were deleted immediately after being transcribed.

### Intensive Interviewing

The interviews followed the semi-structured outline scheduled provided in Appendix B. Preliminary study design included utilizing open-ended probes and questions related to participants' identities and the impact on their experience with HIV, followed by the Social Impact Scale (Fife & Wright, 2000, Appendix C). The Social Impact Scale consists of 24 items that were developed through consultation with clinical experts as well as feedback from PLWHA. The measure assesses enacted, internalized, and anticipated stigma with four sub-scales representing the dimensions of social rejection, financial security, internalized shame, and social isolation. The Cronbach alpha coefficients for these scales range from .85 to .90. Participants are asked to respond on a Likert-type scale (strongly agree, agree, disagree, and strongly disagree) to how much each item reflects their experiences with HIV-related stigma. The measure has been found to correlate with lower self-esteem, personal control, and more negative body image (Fife & Wright, 2000). Items were re-worded to specifically relate to HIV, as the original scale was based on disease in general and utilized a sample that included both PLWHA and those diagnosed with cancer.

While the Social Impact Scale elicits meaningful data, it became clear that for the purpose of this study, the most meaningful data were collected throughout the questions asking about identity and that the information gleaned from the Social Impact Scale was generally redundant. Another early realization was that the fixed-response options for the Fife and Wright scale did not seem to reflect participant experiences. For example, a participant might endorse “disagree” on an item, but in the qualitative follow-up, explain how they have experienced significant stigma in this realm, but had used cognitive reframing as a coping skill in buffering against stigma. For instance, participants said they would disagree with the statement, "I feel some friends have rejected me because of my illness," but then go on to explain that they had in fact lost friends; however, because these people had rejected them, participants no longer considered them friends.

Furthermore, participants seemed most engaged during the identity questions and this portion often took at least 45 minutes to complete because participants had a great deal to share about their experiences. In order to determine the most effective means of capturing participants' narratives, participants were asked which portion of the interview they felt best captured their experiences with HIV. After three participants unanimously agreed that the identity questions seemed most relevant, I decided to forgo utilizing the Fife and Wright scale as planned and instead used the scale as a guide for incorporating follow-up questions and probes about social rejection, financial security, internalized shame, and social isolation. For example, participants might be asked, "In what ways does being a Black woman impact your experience with HIV-related stigma?" After participants gave their unprimed responses, they would be asked follow up questions gleaned from the Fife and Wright scale such as, "Have employers or coworkers

discriminated against you because you are Black woman living with HIV?" if they had not already spoken to stigma experiences in the workplace.

Probes were utilized in order to elicit further detailed information about the experiences participants described. For example, in addition to the questions based on the Fife and Wright scale, participants were asked follow up questions such as the following: Do you feel men and women are treated differently when they have HIV? How do you feel your experience with HIV-related stigma is different as a Black woman as compared to a White woman living with HIV? What type of assumptions do people make about you as a Black woman with HIV?

Following the recommendations put forth by Charmaz (2006), participant comfort and respect was made the number one priority, with the focus remaining on capturing and affirming the participants' perspectives and worldviews. If a participant became distressed with a line of questioning, critical reflection and clinical skills were used to determine the participant's sense of safety and comfort, discontinuing the topic or interview as appropriate. None of the participants interviewed stated that they felt unsafe or uncomfortable and, in fact, many shared that telling their stories was a positive experience. As the interviews progressed, the questions and probes evolved to better reflect burgeoning codes and theories. In addition, member checks throughout each interview to ensure interpretations matched the experiences of participants. In this way, participant responses guided which processes and constructs were most salient in the data analysis.

At the completion of the interview, participants were thanked for their involvement and given an opportunity to ask questions regarding the interview and/or

research being conducted. Subsequently, audio recording was ceased and participants were asked to provide a name and address in order to receive their compensation and debriefing form (See Appendix E). It was made clear to participants that they could utilize a pseudonym and an address of their choosing in order to maintain confidentiality. Participants were compensated with a 10 dollar gift card to a national discount retailer mailed to them with a signed copy of the debriefing form.

#### Data Coding and Analysis

First, the complete transcripts of interviews were read, using open coding to generate a list of concepts and categories and their properties (Charmaz, 2006). Data were analyzed using content analysis techniques (Neuendorf, 2002) informed by the constant comparative method (Glaser, 1998). As elucidated by Charmaz, the initial coding process focused on identifying action (e.g., non-disclosure of status), rather than topic (e.g., heterosexism), language that defined the data in order to reduce bias and the tendency to fit data into pre-existing expectations and concepts. This process included creating tentative labels for the data that summarized what was expressed by participants. This process of open coding led to establishment of preliminary categories within individual interviews, with initial codes reflecting actions depicted by participants so as to minimize researcher bias related to interpretation of meaning. Field notes were completed during and after participant interviews in order to review the interview process, identify potential researcher bias, and allow for a critique of the survey structure and content. Data analyses utilized inductive and deductive processes, with new themes and categories created as they materialized from the data and existing categories and themes guiding subsequent coding.

After completing this process with all of the interviews, the cross-interview comparison process began. Codes that described connections between labels and initial codes were identified. Once a strong analytic direction had been established through the initial coding processes, the focused coding process began, entailing a detailed review of identified concepts and the relationships between categories. Categories were compiled into themes, which provided a theoretical structure that reflected relationships between identified codes and categories.

Throughout the coding and data collection process, comparisons of incidents, interviews, and categories were conducted systematically in order to identify the similarities and differences between them (Chamberlain, 1999). This process supported a mutually informative relationship between data collection and theory development. Results were summarized with verbatim quotations selected to illustrate identified categories, themes, properties, and processes. Quotations were chosen with specific criteria in mind; namely that they effectively demonstrate the relevant theme and maintain the confidentiality of the participant. Any identifying characteristics mentioned in the quotations used were altered or excluded to ensure the anonymity of the participant's identity. Furthermore, by presenting participant quotations in addition to the identified themes, the reader may reflect on the interpretations provided and engage in their own reflection on the data.

#### Validity, Reliability, and Minimizing Bias

As noted previously, it was not possible for the researcher to approach this topic without preconceived notions and biases due to prior experiences working with PLWH and knowledge of the existing literature. In order to support the validity of the data, the



researcher was particularly intentional about engaging in thorough reflection of how her own assumptions may be shaping the data coding process; therefore member checks and reflexive exploration of the data was utilized to reduce bias and foster validity in capturing participants' meaning and experiences (Johnson, 1999; Whittemore, Chase, & Mandle, 2001).

The integrity and criticality of the data was fostered through repetitive and ongoing checks of interpretations (Ambert, Adler, Adler, & Detzner, 1995) throughout data collection and coding. This process entailed member checks, which consisted of reflective statements made back to the participant in order to clarify the accuracy of the data and effectively capture participants' tone and meaning. In this manner, emerging relationships were verified throughout the data collection process by asking participants to share their reactions and thoughts to these theories and to offer reasons for the patterns observed (Brewer & Hunter, 2006; Guba & Lincoln, 2001; Huberman & Miles, 2002). This process not only reduced researcher bias, but empowered the participant as the expert of their own experience.

By monitoring the developing constructions and employing reflexivity throughout the data collection process, the development of categories and themes was approached with critical reflection and self-awareness in order to minimize bias and support the integrity of the research (Johnson, 1999; Shenton, 2004; Whittemore, Chase, & Mandle, 2001). Furthermore, interrater reliability was assessed by reviewing coded interviews with a research assistant and engaging in discussion of discrepancies in data interpretation and coding. Only one discrepancy occurred and was resolved via exploration of the data context as provided by the participant.

Theoretical memos, or records of developing ideas about codes and their interconnections (Glaser, 1998), were also used to document thinking processes throughout the data collection and coding process. Theoretical memos provided a preliminary analysis of the transcripts and aided the formulation and clarification of relationships between codes and categories. For example, the following theoretical memo is included to illustrate early conceptual thinking related to the relationship between the codes "stereotype threat" and "symbolic stigma" and includes the associated participant and transcript section:

Participant describes reticence to disclose his drug use, as he fears that this will reinforce negative stereotypes about the Black community and PLWH (stereotype threat) [Participant number 0610151200, Transcript line: 10Subshow]. He describes feeling stuck, between wanting to seek help and support, but feeling as if his needing help would reflect badly, not just on him, but the broader communities he is a part of as a Black gay man and reinforce the belief that he “deserved” HIV (symbolic stigma).

In order to add structure to the manual data analysis process, qualitative data analysis software (NVivo) was also utilized to facilitate interrogation of the data and reliability of results. While the use of software analysis is limited in its ability to capture the fluidity and context of themes (Welsh, 2002), NVivo 11 was utilized to support the analysis, navigation, and management of the data (QSR International, 2015). Coded interview transcriptions were imported into the NVivo system and analyzed to examine the relationships between themes, categories, and codes within the data. The coded data were collected into nodes, or a collection of references regarding a specific category or theme. Nodes were used as containers and organized in hierarchies, from more general codes at the top (parent node) to more specific codes (child, grandchild, and great-grandchild nodes) as a way to organize the data based on theme. The following provides an example of a node hierarchy used for this study:

#### Race (parent node)

- HIV-related stigma within the Black community (child node)
  - Symbolic HIV-related stigma within Black community (grandchild node)
    - Stereotype threat (great-grandchild node)
  - Avoidance of HIV within the Black community (grandchild node)
    - Stigma Burnout (great-grandchild node)

Software analysis allowed for the aggregation of nodes (gathering all content within the parent node) and comparison of themes and categories across participants based on demographic data and codes. NVivo also allowed for analysis of data between and within interviews, which was helpful in exploring the validity of the researcher's impressions of relationships between codes, categories, and themes.

#### Theoretical Saturation

Qualitative research within the health sciences commonly requires theoretical saturation to determine sample size and is the gold standard by which purposive sampling sizes are determined (Guest, Bunce, & Johnson, 2006). Theoretical saturation is generally defined as the point at which additional data no longer contribute to the development of the properties of a category (Glaser & Strauss, 1967). However, there exist limited data that indicate how saturation should be determined or operationalized. Furthermore, while the present study was purposive in its sampling regarding HIV status, the independent variables of interest (identity intersections) were not restricted and, therefore, the units investigated were less selective than typical purposive sampling approaches. The decision to not restrict sampling based on identity was intentional as a means of addressing limitations in existing research which relies on sampling restrictions as proxies for identity constructs; however, by not restricting identity constructs of interest, the issue of theoretical saturation within the present study is further complicated.

The present study's resulting sample was largely represented by PLWH who identified as Black (only two participants identified as White) and all identified as either MSM or WSM. As a result, the identity constructs being explored were less extensive than they could have been and, after twenty-one interviews, the codes developed from the data were recurrent and reflected previously identified themes. These findings are consistent with those of a study by Guest, Bruce, and Johnson (2006) examining data saturation among a purposive sample of women at high risk for HIV, which found code definitions and variability to be fairly stable after twelve interviews with the improvement in coding stability diminishing substantially after twelve interviews. As the vast majority (91%) of the present study's participants can be considered as constituting two comparison groups, Black MSM and Black WSM, a sample size of 21 is consistent with recommendations for examining differences between two groups within qualitative research (Johnson, 1998), particularly given the nature of the topic, quality of data, and use of abductive analysis and grounded theory methodology (Morse, 2000).

The next chapter describes the results of the present study. The results are organized based on theme, with the corresponding categories and relationships that emerged from the data described below.

## CHAPTER 4: RESULTS

The purpose of this study was to explore and describe how the intersecting identities of PLWH impact personal experiences of HIV-related stigma. Twenty-one participants living with HIV were interviewed and described their experiences with HIV-related stigma and the ways in which their various identities shaped these experiences. In this chapter, I provide a comprehensive description of the themes and categories that emerged through the data analysis and are pertinent to this study's research questions. After conducting 21 interviews, the data clearly indicated several themes that reached theoretical saturation via consistent and recurring patterns of codes and categories that elucidate the impact of intersecting identities on the experience of HIV-related stigma among PLWH and substantially contribute to the existing literature.

### Findings

This study utilized an abductive approach to explore how intersecting identities of PLWH impact their experiences with HIV-related stigma. Participants identified several identity constructs as significant in shaping their experiences with HIV-related stigma, including gender, ethnicity/race, and sexual orientation. Participants described how these identity constructs intersected within broader systems, such as institutions, local community, religion, and historical context, to impact their experiences with HIV-related stigma and related social processes (such as racism, sexism, and heterosexism).

Before directly addressing the research questions, this section will present a brief overview of the general stigma experiences reported by participants to provide context. The data indicated that all of the participants reported experiencing both symbolic and instrumental HIV-related stigma. All participants reported experiencing negative judgments from others based on their positive HIV status, including assumptions that participants were promiscuous or engaged in sex work (67%), engaged in IDU (48%), deserved HIV because they were MSM (100% of MSM), or experienced a more ambiguous and general critique of their morality based on being HIV positive (43%). In terms of instrumental stigma, participants reported experiencing avoidance or distancing behaviors from others as a result of misinformation about transmission and prognosis (95%) and perceptions that their positive HIV status threatened their perceived competency or ability to contribute to society (71%). Participants identified both anticipated symbolic and instrumental stigma as a reason for non-disclosure of their HIV status to others (62% and 52%, respectively).

An examination of participants' responses indicated that the stigma experienced by participants came from a variety of sources. Participants reported experiencing HIV-related stigma from family (57%), friends (29%), co-workers (29%), church members (29%), and medical providers (29%). Interestingly, the reports of sources of HIV-related support mirror those of stigma in that participants mentioned receiving HIV-related support from family (52%), friends (24%), medical providers (24%), co-workers (14%), and partners (14%). The data seem to reflect the impact of exposure and salience of relationships in predicting both stigma and support experiences, in that the more

interactions with a given person or group, the higher likelihood of a variety of experiences (both positive and negative). As these data reflect, participants reported experiencing HIV-related stigma frequently and within a diverse range of relationships and contexts. As the remainder of this section will exhibit, the HIV-related stigma experiences reported by participants differed based on participants' identities and the related sociocultural context.

It should be noted that several categories were universal across the interviews and it was common to have a participant's response reflect a number of codes and categories that fit under multiple themes. This was expected, as intersections of identity reflect an overlap of interrelated, rather than distinct, constructs. As such, the reader will likely note some overlap across the themes presented. Verbatim quotes are utilized to provide context and serve as examples of the themes and codes described. When appropriate, additional background information and/or context are provided in brackets. When selected quotes included identifying information or names of agencies where participants received services, the identifying information was replaced with a description of the person's role or type of agency to protect confidentiality. See Appendix F for the coding frame used for this study.

#### Research Question 1: Which identity constructs are most salient in impacting PLWH's experiences with HIV-related stigma?

Participants most commonly reported race, sexual orientation, and gender as compounding their experiences with HIV-related stigma. The data indicated a mutually reinforcing relationship between HIV-related stigma and racism, sexism, and heterosexism, in that the social meaning attributed to being HIV positive (e.g., "dirty" or

"immoral") was used to reinforce racist, anti-gay, and sexist stereotypes and conventional sociocultural values and norms. Discriminatory beliefs shaped how participants experienced HIV-related stigma, in that stereotypes and conventional values determined the assumptions and judgments others made about participants' HIV status. The categories that emerged are organized by identity construct below (race, sexual orientation, gender, and navigating multiple marginalized identities) and are presented in Table 2.

### Theme 1: Race

Eighty-six percent of participants identified ethnicity as a factor that impacted their experiences with HIV-related stigma. This number includes all participants who identified as Black MSM and all but one of the participants who identified as Black WSM. Both of the participants who identified as White stated that they did not believe race impacted their personal experiences with HIV-related stigma, but acknowledged that race impacted HIV-related stigma for people of color living with HIV. Participants described race as impacting their HIV-related stigma experiences in two significant ways. Firstly, HIV-related stigma was reported by participants as being experienced as an extension of, or used to legitimize, racist beliefs. Secondly, participants spoke to the ways in which racism impacted the Black community's response to HIV and PLWH. These processes are explored in more detail below. The codes related to race that emerged from the data are presented in Table 3.

Racism and the Social and Structural Context of HIV (19 participants, 100% of Black participants):



All of the participants who identified as an ethnic minority described experiences with racism at individual, institutional, and/or structural levels. In fact, many Black participants responded to the question of how race impacted their experiences with HIV-related stigma by first describing the social consequences of racism that contribute to HIV risk and general discrimination, rather than describing specific HIV-related stigma experiences. While the sociocultural contributors to HIV risk within the Black community are distinguished from HIV-related stigma experiences, the social consequences related to marginalization (e.g., substance use, sex work) reflect the same circumstances that contribute to not only HIV risk, but symbolic HIV-related stigma. The data indicated that the sociocultural context that HIV-related stigma was experienced within was very salient for participants; therefore, it seems pertinent to consider both the stigma experiences themselves, and the sociocultural circumstances within which they occurred. For example, participants spoke to the evidence of racism across social systems and described how racism manifests in the form of inequity, disadvantage, and threats to safety. The following excerpts reflect the social consequences of racism reported by participants:

I think a lot of Black people, we get arrested for shit White people walk away from and then, you know, you're like...it gets messed up because you won't get a job and then, being in prison, it makes you hard and you learn not to count on anyone. (40-year-old Black WSM)

...I think about how incarceration and the drug epidemic, like, crack in the 80s and 90s. And racism and all of those horrible things have kept Black people down. And it...makes it so much harder and you don't know how long you can fight like that. (49-year-old Black WSM)

These children are vulnerable. They don't use protection. Especially African Americans. There's no father figure in the house, the African American women are strung out on drugs, their children are vulnerable and can do anything they

want to and they are trying to find love in the wrong places. The [HIV] epidemic spreads. (60-year-old Black MSM)

Member checks indicated that participants wanted to highlight the impact of the structural and social context that contributed to their HIV risk and HIV-related stigma experiences. Black participants described how the negative effects of the discrimination and marginalization they experience (e.g., substance use, poverty, incarceration, and HIV infection) are dismissed by those in power, and instead used as evidence to support the legitimacy of racially based stereotypes that blame them for being HIV positive. The following excerpt illustrates one participant's description of how the social consequences of racial marginalization are framed as the Black community's problem, rather than acknowledging the responsibility and role of discrimination and disparities in privilege and power:

You see these statistics on TV about the Black community and it's crazy, you know, being a young Black man. It's like, there's all this stuff out there that paints us in this picture that isn't accurate. I think White people misinterpret what they see. The media makes it look like we're all using drugs and going to prison. And there is some of that. I'm not trying to ignore what's out there. But it's because of all this other shit, like, poverty and racism and all that... (27-year-old Black MSM)

Overall, Black participants' reports indicated a sense that HIV among the Black community is generally considered by society to be a deserved consequence due to personal mistakes and deficiencies, without consideration of the role of racism in shaping social circumstances and personal efficacy. Furthermore, the HIV-related stigma reported by Black participants reflected how racism is used to blame Black PLWH. Participants shared that others assumed that they must have "deserved" HIV by engaging in IDU, sex work, or promiscuous sex based on racial stereotypes. These data are presented below.

Racism and Symbolic HIV-Related Stigma (13 participants, 68% of Black participants):

The majority of Black participants endorsed feeling as if racism compounded or shaped their experiences with HIV-related stigma. In particular, participants described how others made assumptions and judgments about their behavior and blamed them for getting HIV based on their racial identity. Participants shared that, because they were Black, others assumed they must have gotten HIV through behaviors that are commonly depicted as morally egregious or reflective of a personal deficit and therefore “deserving” of HIV. The following excerpts depict the general messages of blame participants experienced based on their identities as a Black person living with HIV:

I think being Black, it's like we're supposed to get [HIV] because of where we live or 'cause we're seen as asking for it. And if you're White and you have HIV, then it was not your fault. Like, maybe you just got caught up in the wrong place at the wrong time. So if you're Black, it's your fault, but if you're White, then it was someone else's fault. (40-year-old Black WSM)

It's about being hypocritical. For White people, it's like, they must have gotten it from someone who's Black or other color and that's the only reason they got it is because they were messing with us Black folk. But if you're Black, then it's your fault. Ain't nobody gonna say, "Oh no, who gave this to you?" It's, "What did you do to get this?" You hear? They blame it on us. (51-year-old Black MSM)

Being Black and gay, I think people assume I must have done something to deserve it. (44-year-old Black MSM)

Participants spoke of the specific assumptions and judgments they experienced, or anticipated, from others as a Black person living with HIV and described how blame was communicated via assumptions about transmission method or risk behaviors:

I think [the doctor] thought, "She's dirty. She's a prostitute." You know? People assume. If you're Black, you get judged. Even other Black people. If you got HIV, then it's like, you know, what did you do? How'd you bring this on you? (54-year-old Black WSM)

[The doctors] see me and hear my husband was in prison and they think I don't know any better. If you Black, they be like, "Who you sleeping with? What drugs you taking? Where are you...hanging?" Or stuff like that...If you Black, it's your fault. Automatically. (43-year-old Black WSM)

I think people still think of HIV as an African disease. So, it's like there's this preconception that if you're Black, then you already going to be judged...if you're Black, then you must be doing something bad, uh, like, of course you're going to get HIV. There's this assumption that you're being immoral or you're dangerous or something. I know for me, I think the first thing people want to know is, was I prostituting? That's the first thing that pops into their head because of all these preconceptions...Like that friend I was telling you about. She uses needles for her insulin for type 2 diabetes, but the doctor, he still thought she was shooting up 'cause he made assumptions about her being Black. (38-year-old Black WSM)

Participants also described being blamed or faulted for being HIV positive via assumptions that they had acquired HIV because they were ignorant or uneducated based on their racial identity as a Black person:

Because I'm Black, people automatically assume I'm uneducated. They don't always say it, or at least, they don't say with their words, but I can tell by how they say things or what they say. So they might assume I'm positive because I didn't know any better. (49-year-old Black WSM)

As the data indicate, Black participants described how racist stereotypes that depict Black people as incompetent, criminal, or lacking self-control seem to underlie the assumptions and judgments others made about how they were infected with HIV and the amount of blame ascribed to being HIV positive. In other words, Black participants described how their positive HIV status was interpreted through the lens of racist stereotypes. Racial stereotypes and prejudices seemed to have impacted not only the stigma enacted by non-Black others, but also the experiences of HIV-related stigma enacted within the Black community toward Black PLWH.

HIV-Related Stigma within the Black Community (17 participants, 89% of Black participants):

Almost all of the Black participants shared experiences of HIV-related stigma within the Black community and spoke directly to experiencing HIV-related stigma from other Black people in the form of being judged as “dirty” or avoided. Several Black

participants shared that they felt the HIV-related stigma they experienced from other Black people was particularly salient and acute:

[The Black community responds to PLWH with], "Oh, she nasty. She got the AIDS." They treat you cold. They say nasty things to you...When you think HIV you think prostitutes and druggies and, you know, like dirty people. That's what they think if you Black...They don't know [about HIV]! They have their preconceptions and that's all they have...[especially in the Black community]. No one wants to talk about it because you think HIV, you think prostitution. You think being gay, you think dirty. [It's more intense in the Black community]. 42-year-old Black WSM)

In the African American community, we don't want to hear that. We don't want to hear nothing about no HIV. People say, "That punk got AIDS," or, "That sissy got AIDS. That nigger got AIDS." Sarcasm ways. (56-year-old Black MSM)

Participants' narratives provided insight into why HIV-related stigma was experienced as particularly intense within the Black community. For example, when asked how being Black impacts her experiences with HIV-related stigma, the woman quoted below noted that both White and Black people judge her for being HIV positive, but that the judgment that occurs within the Black community is, at least in part, motivated by fear of confirming racial stereotypes (i.e., stereotype threat) and negative evaluations:

Because I'm Black and have [HIV], they assume I'm dirty. Like I must have been drugging or sleeping around. White people get treated better by both White *and* Black people. It's not just White people; Black people do it to Black people. We're hard on each other. We want better lives for each other and when someone messes up, it's really hard to see (51-year-old Black WSM).

The participant quoted above refers to being HIV positive as "mess[ing] up," inferring that Black PLWH are viewed as being personally at fault for being HIV positive. In stating, "We're hard on each other. We want better lives for each other...", she refers to the pressure the Black community experiences to avoid confirming negative racial stereotypes and be free from being defined by such stereotypes. As this excerpt

reflects, Black participants' descriptions of HIV-related stigma experiences within the Black community illustrated the influence of racial stereotypes on the manner in which the Black community addresses HIV. The data suggested that fears of confirming negative racial stereotypes result in distancing efforts (e.g., HIV-related stigma and avoidance) within the Black community as a way to buffer against further discrimination. In other words, participants described how the very act of addressing HIV and HIV-related issues within the Black community risks creating an association in others' minds between Blacks and the negative connotations related to HIV (e.g., "dirty," blame), reinforcing negative racial stereotypes and increasing the likelihood of discrimination. The fear of confirming stereotypes of one's group is referred to as stereotype threat (Steele, Spencer, & Aronson, 2002), and as noted in the literature review, stigma can be partially understood as a coping strategy that serves to distance oneself from a discredited group, thereby reducing the threat of being associated with the negative attributes and consequences related to the stigmatized group. The processes of disengagement and distancing within the Black community that were described by participants included explicit judgments of PLWH (e.g., being labeled "dirty" or "nasty") or assumptions of IDU, promiscuity, or other behaviors that are commonly viewed as iniquitous:

[The Black community responds to PLWH with], "Oh, she nasty. She got the AIDS." They treat you cold. They say nasty things to you...When you think HIV you think prostitutes and druggies and, you know, like dirty people. That's what they think if you Black...They don't know [about HIV]! They have their preconceptions and that's all they have...[especially in the Black community]. No one wants to talk about it because you think HIV, you think prostitution. You think being gay, you think dirty. [It's more intense in the Black community]. 42-year-old Black WSM) (42-year-old Black WSM)

[HIV-related stigma] is worse for Black people. It is. It is. It is. There's less stigma in Hispanic and even any other race. Black people, I don't know. I know they know [about HIV]. It's all on the buses, you know. They are trying to educate

their people. I don't know, it's like they need something to make them look better than other people. I think they all have the wrong concept. A lot of Black people think that people who are HIV positive are, like, very promiscuous. Or they been prostitutes or, you know. All these stereotypes. "Yeah, you got that 'cause you nasty." (61-year-old Black WSM)

The latter participant quoted above suggests that the Black community avoids HIV education in an effort to "look better than other people." Given the context, this statement seems to reflect the Black community's struggle to maintain a sense of worthiness within the context of pervasive racism and marginalization. From this perspective, acknowledging HIV leaves the Black community vulnerable to being associated with the negative labels commonly attributed to PLWH (e.g., "dirty,") and further discrimination in the form of being blamed for the risk factors associated with HIV (e.g., IDU, sex work), both of which risk reinforcing racist stereotypes. The below excerpt provides an example of one participant's description of how stereotype threat results in avoidance of HIV-related issues within the Black community:

...ain't nobody want to talk real about HIV in the Black community. So we are scapegoats and nobody is offering any assistance. We got people dying and White people are just looking the other way. Hell, even Black people, we looking the other way 'cause we don't want to admit it 'cause we know we gonna get blamed for it. (51-year-old Black MSM)

As the above excerpt indicates, distancing and disengagement efforts within the Black community were identified not only in the form of explicit judgments and assumptions, but also in the form of avoidance and silence within the Black community in regard to discussing, acknowledging, and addressing HIV.

Avoidance of HIV within the Black Community (16 participants, 84% of Black participants):

Seventy-nine percent of Black participants described ways in which the Black community responds to HIV with avoidance. As described previously, disengagement

from HIV within the Black community was commonly framed by participants as an effort to avoid confirming negative stereotypes; but was also framed as a consequence of taxed emotional and mental resources resulting from the experience of ubiquitous racism. For the purpose of this study, this theme was coded as “stigma burnout,” and represents Black participants' descriptions of the Black community's reluctance to engage with HIV in an attempt to avoid compounding experiences of emotional distress due to overly taxed mental resources as a result of existing marginalization. The process of stigma burnout is comparable to engaging in explicit judgments of PLWH (i.e., symbolic stigma) in that both aim to reduce negative psychosocial experiences via distancing; however, stigma burnout does not reflect the "othering" and blame inherent in symbolic stigma, but rather a less aggressive approach of withdrawal and avoidance. This process is inherent in participants' descriptions of HIV as an additional burden on top of existing struggles within the Black community. For example, one participant named being overburdened with other sources of stigma as a reason why his family avoids addressing his positive status directly and openly:

[My mom] doesn't want to talk about [me being HIV positive]. Same goes for my brother and sister. They know, but we don't talk about it. The stigma is bigger for [Black people] because there's all these other stigmas we face and people, like, they don't want to have to deal with one more thing. (27-year-old Black MSM)

Another participant mirrored this sentiment with the following response when asked about the impact of race on HIV-related stigma experiences:

They don't know [about HIV]! They have their preconceptions and that's all they have...[especially in the Black community]. [It's more intense] 'cause being Black is hard enough. People don't have room for more pain... (42-year-old Black WSM)

The weariness inherent in the above quotes speak to detrimental consequences of the marginalization and racism the Black community experiences, with participants



describing how drug use, incarceration of Black men, and poverty leave the Black community mentally taxed and less able to process additional stressors. The data illustrate the ways in which avoidance, distancing, and stigma regarding HIV within the Black community serve to divide and disempower the Black community, resulting in reduced support for Black PLWH:

Nobody wants to talk about HIV in the Black community. There's a hush around it, or, like, a strong reaction against it. When someone is talking about someone who has HIV, its, "The AIDS." Not HIV. No one really knows what it means. It's like a death sentence. Like you're marked...people are still not really talking about [HIV], unless you're at group or you're at the doctor. I think if you're Black and you have HIV, in a lot of ways, you are on you own... (35-year-old Black MSM)

As the data indicate, Black participants experienced HIV-related stigma as an extension of racism in the ways in which it is used to confirm and reinforce stereotypes and perpetuate processes that serve to disempower the Black community. In fact, the theme of HIV-related stigma serving to reinforce marginalization of minority identities was consistent throughout the data and was evident in participants' descriptions of having their HIV status construed as a punishment for, or a natural consequence of, having an identity that challenges conventional sociocultural norms, beliefs, or values. For example, participants who identified as MSM described HIV-related stigma that served to legitimize or justify anti-gay beliefs that paint same-sex relationships as unnatural or immoral.

## Theme 2: Sexual Orientation

Sexual orientation was identified as a factor in shaping HIV-related stigma experiences by all MSM participants. The data indicate that MSM participants experienced anti-gay messages and discrimination across systems, including interpersonal relationships and broader societal and cultural structures, which manifested

as HIV-related stigma in the form of messages of blame for having HIV based on their sexual orientation. Codes related to sexual orientation are presented in Table 4.

HIV as Punishment for being Gay (19 participants, 91%):

The impact of sexual orientation on HIV-related stigma was apparent in MSM participants' descriptions of having their HIV status considered by others as a punishment for being gay or a natural consequence of being gay:

...there's this idea that HIV is punishment for being gay... [My family] never said I deserve it, but have said this wouldn't have happened if I wasn't gay... (31-year-old White MSM)

There's definitely this stigma about being gay and, like, you deserve HIV. Like, "What did you expect?" (27-year-old Black MSM)

"Well, if you weren't no faggot. If you weren't no punk. If you weren't gay, you wouldn't have [HIV]." But no, you wrong about that. (56-year old Black MSM)

If you weren't gay, you wouldn't be positive...it's like, "Well, you deserve it"... [My ex-wife] told my [children], "Your dad is a pervert, he got himself the AIDS." (60-year-old Black MSM)

As the last excerpt above reflects, much of the HIV-related stigma and anti-gay beliefs reported by MSM participants were related to beliefs that being gay is immoral, a perversion, and/or against religious edicts. In fact, thirty-three percent of participants reported the influence of religious beliefs in shaping anti-gay beliefs that construe HIV as punishment for being gay:

[Being gay], there's a sense that you deserve it. (35-year-old Black MSM)  
There's this idea that you deserve it. Like you're going to hell and this is just another one of God's punishments. (20-year-old Black MSM)

But you hear about how HIV is God's way of punishing sin and being gay and all that. In those ways, you get blamed...I think people...think I deserve [HIV] because I'm gay. It's synonymous with gay and so, people see it as proof that being gay is wrong and that's God's way of saying that. (44-year-old Black MSM)

Instances of anti-gay sentiments and behaviors were also evident in the responses of participants who identified as WSM. Approximately half (56%) of the participants who identified as WSM expressed anti-gay beliefs and indicated that they viewed MSM as deserving of HIV as is exemplified in the selected excerpts below:

[Referring to MSM] God made woman for man. He didn't make no man for a man. That's not how it is. You go against God, you asking for it. I was doing right by my family and because of my husband's sins, because *he* went against God, I got it. That's my burden to bear, but I ain't deserved it like these boys that like boys and all that nonsense. (43-year-old Black WSM)

[Gay men] got it by having all this sex with all these people and I didn't do nothing like that...they know what they doing. It's dangerous, so they already know...this could happen...they don't have shame about it! They just talk about it like it's just another thing. (54-year-old Black WSM)

Similar to the stereotype threat related to racist stereotypes reported by Black participants, participants who identified as MSM described fearing that their positive status would lend credence to such anti-gay beliefs, such as HIV being a "gay disease" or a punishment for "sinning":

I hate proving people right. They already assume [I got HIV through MSM contact] and it's true. So I feel like a walking stereotype. It's embarrassing and I don't tell anyone specifically that's how I got it, but they make the assumption. So sometimes, it's like they were right. I'm proving them right and I hate that...You never know how people are going to feel about [being gay] or treat you. It's like, you know that I am gay. Ok, that's one thing to handle. Then, you have to put HIV on top of that...It's weird because you don't know if you are being discriminated against if you're gay or if you're HIV...it could be all of them...All you know is that people are being weird around you...And you don't want to prove them right!...There is already this idea that if you're gay, then you're doing something wrong. And having HIV is like saying, "Yup! This is my punishment for sinning. This is what I get." (31-year-old Black MSM)

The participant quoted above refers to concerns that being HIV positive reinforces beliefs that he was "doing something wrong," a sentiment that several MSM participants echoed in their interviews. Specifically, MSM participants indicated that not only did

they experience stigma around the act of same-sex sexual activity, but also noted stereotypes of MSM as sexually promiscuous or engaged in drug use:

Being a gay male, I mean, the stats and facts...The majority of HIV people are gay men and people assume if you are a gay man, you are being promiscuous...A lot of people look at [being gay and HIV positive] like, "Oh, you were out there being fast or promiscuous." But no, it wasn't like that. There are different ways of getting it. There are assumptions that I wasn't being careful. (24-year-old Black and Puerto Rican MSM)

People assume a few things right away. First, that I'm gay and that I was promiscuous and got myself into this trouble. (31-year-old Black MSM)

[People assume I was] sleeping around and being amoral. (20-year-old Black MSM)

These responses indicate that MSM participants experienced stigma based on not only their identity as a MSM, but also experienced stigma related to the behaviors associated with MSM based on stereotypes. As described earlier, participants described moral judgments against being gay; however, the data indicate that MSM are further stigmatized due to the related, but distinct, notion that gay men are associated with promiscuity, unprotected sex, and substance use. As a result, MSM participants experienced stigma in the form of having their HIV status interpreted by others as a consequence or punishment for engaging in behaviors deemed immoral or unnatural by others.

Again, the data related to the impact of sexual orientation on HIV-related stigma experiences indicate the role of HIV-related stigma in reinforcing conventional values that may serve to discredit marginalized groups. This theme was further reflected in the data elucidating the impact of women's gender identity on their HIV-related stigma experiences, in that blame and judgment were focused on women's perceived deviation

from gender-based sexual norms and values, as well as served to maintain gender-based power differentials.

### Theme 3: Gender

Eighty-one percent of participants identified gender (75% of MSM and 89% of WSM) as an influential factor in shaping their experiences with HIV-related stigma. The MSM who reported gender as a factor in shaping their experiences with HIV-related stigma explained that being HIV positive was often seen as synonymous with being gay, and that being gay was seen as conflicting with expectations around Black masculinity. Therefore, both being HIV positive and having sex with men contributed to increased levels of perceived stigma among MSM in that both threatened their identity as a Black man. The impact of the intersections of gender, race, and sexual orientation on the HIV-related stigma experiences of Black MSM is explored more fully under research question 2. Women, on the other hand, noted that gender impacted their experiences through assumptions about promiscuity and sex-based blame. Both men and women reported gender as a contributing factor in how being HIV positive shaped threats to their perceived competency and contribution due to socially constructed gender roles that cast women as caregivers and men as financial providers. Codes related to gender are presented in Table 5.

Female Sexuality and HIV-Related Stigma (9 participants, 100% of female participants):

Every woman interviewed shared ways in which their HIV status resulted in presumptions and judgments around their sexual history and sexual behaviors, specifically that they must have been promiscuous, engaged in sex work, or some other sexually-related behavior that was "deserving" of HIV. Sixty-seven percent of all

participants, and 100% of female participants, described how women's sexuality is often seen as taboo or moralized. The excerpts below reflect the assumptions and judgments about their sexuality and sexual choices female participants experienced as women living with HIV:

[People assume] that I must have been wild or been with the wrong guy... (49-year-old Black WSM)

People think you must be fast, like you're going around acting immoral and getting into trouble...If you're a woman, you're gonna get blamed. 'Cause it's all, "You shouldn't a been sleeping with that man or shoulda been more careful or you're acting loose and asking for it." (51-year-old Black WSM)

...the doctors, they talked to me about it. They are asking about, like, do I do drugs and who am I sleeping with and have I ever, you know, prostituted myself. It was disrespecting. (54-year-old Black WSM)

I think the first thing people want to know is, was I prostituting. That's the first thing that pops into their head because of all these preconceptions. (38-year-old Black WSM)

Women spoke directly to the contradictory standards regarding sexuality between men and women, noting that women's sexuality is moralized, while men (specifically MSW) are given sexual agency and power. Thirty-three percent of the women interviewed spoke to a gendered double standard around promiscuity and multiple sex partners:

For women, they get labeled. So people will say, "Oh, you a prostitute, you a ho, junkie, nasty ass slut," or something. But men don't get that. They can get high, sleeping with all the women they want, and that's ok. It's like, "Oh, that's what men do." So if you're a woman, you got to prove your respect. It's like...(sighing), so men already get respect, but if you're a woman, you have to prove you deserve respect and you lose it easier than a man does. A man gets to do that stuff because, it's like, men will be men. Like that stupid saying. But a woman can't be like that. You mess up as a woman, you are a slut, a prostitute, a whore. It goes on and on. (40-year-old Black WSM)

You know, men, they allowed to do what they want. They gonna be men...You know how men are! They never satisfied with one woman and so they gonna get

what they can get. So a lot of women, they just say, well, that's the ways it is! (43-year-old Black WSM)

'Cause a man can have sex with as many women as he wants. He could be sleeping with everyone and people would just slap him on the back and say, "Good for you!" (51-year-old Black WSM)

Participants' responses described how taboos around women's sexuality shape HIV-related stigma beliefs, resulting in beliefs that cast HIV as a punishment for deviating from socially constructed values that suppress and castigate women's sexual agency. Not only did women's reports indicate that they experienced a disparate amount of blame related to sex, they also spoke to concurrent sociocultural processes that serve to disempower women's agency in relationships and sexual negotiation. Female participants described how women are held accountable for sexual negotiation while receiving concurrent and contradictory messages that shame women for having sexual agency. Sixty-seven percent of female participants described expectations around sexuality and responsibility for sexual negotiation (e.g., HIV prevention) based on gender. The following excerpt exemplifies the sociocultural messages described by female participants that suppress female sexual agency and inhibit conversations around HIV risk and the ability to negotiate for safer sex practices:

It is hard for women, you know, to talk about being a sexual being. You're told that you aren't supposed to be like that. Like you're dirty for even wanting it, but then at the same time, the message is that sex is all you're good for. It's an awful thing, and I hope it's getting better for these younger women. Because it's terrible to be in that position. And I think it's a big part of why I felt so embarrassed and why I didn't know how to have these conversations with my husband...I don't know if you know this, but HIV among Black women is a big problem. We have higher rates except for, I think, just gay men. But then it's us. And I think this happens for a few reasons. I know for me, a big part was, after my husband got back from prison, I didn't know how to talk about whether I needed to use a condom or to talk about HIV risk or nothing like that. I think women, especially Black women, we're not comfortable talking about sex. And to protect yourself, you got to know how to talk about sex and sexuality and being healthy. I know

my mama never talked to me about sex. Nobody did. If she knew I was having sex, she would have whooped me. It was all this dark mysterious thing...I think it all adds to the stigma. If you stop having stigma around sex, then you can talk honestly about HIV and protection. (49-year-old Black WSM)

The above excerpt reflects the contradictory messages women receive around sexuality, in that women are simultaneously sexualized and judged for their sexuality. Overall, the data indicated that for the women interviewed, HIV-related stigma often took the form of blame for perceived deviations or violations of sociocultural gender expectations regarding female sexuality. Gendered expectations were also apparent in participants' descriptions of how their perceived competency and contribution were threatened as a PLWH, in that women experienced threats to their perceived competence as caregivers and men reported threats to their role as financial providers.

Gender and Threats to Perceived Competency (15 participants, 71%):

Participants shared experiences and beliefs that reflected instrumental stigma in the form of threats to their perceived competency and ability to contribute to society based on their positive HIV status. Responses indicated that culturally prescribed gender norms impacted the competencies and contributions that participants identified as threatened by their positive HIV status. In other words, male participants were more likely to report ways in which being HIV positive threatened perceived ability to provide financially, gain employment or education, while women were more likely to indicate that their positive HIV status threatened perceptions of their ability to adequately care for their children or grandchildren. While 67% of male participants spoke to concerns around the impact of being HIV positive on their employment or education, only 33% of female participants voiced these concerns. Men spoke to sociocultural expectations of men to be the financial providers and shared that being HIV positive challenged their ability to



provide for their family or partners. For example, one participant spoke of his responsibility to provide financially as a man:

...the bible says the man is the breadwinner, it's like that. Being a man, you feel as though you need to be contributing more. There's a lot of pressure...Sometimes I wish I was back in the work force, doing food service. Then I got a job as a quality inspector. The money I was making compared to disability was astronomical. But due to the doctors saying he wrote me off as being a disabled person. At times, it gets to the point where I could be doing more. You know, but the body don't want to act right. (56-year-old Black MSM)

Male participants' responses reflected ways in which being HIV positive interfered with their ability to meet competencies that reflected cultural expectations around masculinity. In fact, one participant spoke directly to how masculinity, not just gender itself, had shaped the pressure he experienced to be the financial provider within his relationship. Although both he and his partner are male, he reported taking on the role of financial provider because he was the "more masculine one" in his relationship:

I want to be able to take care of my spouse, but I can't right now. I feel bad about that. He's, you know, more feminine than I am, I feel like I need to take care of him. I guess being the more masculine one in the relationship, I feel like it's my duty to be able to take care of us financially. And when I'm sick, I can't do that. (31-year-old White MSM)

The participant quoted above expressed guilt and frustration about being ill and, therefore, unable to work and provide for his partner. Another participant's response echoed the impact of being HIV positive on meeting expectations around masculinity. When asked if people view him as less competent because he is HIV positive, he shared that his ability to feel "dominant" and physically capable was reduced by his HIV symptoms:

There are certain things people help me to do in some situations. Like something too heavy, like, "Don't carry that." They are cautious about making sure I am ok. It doesn't mess with me. Some people would take it another way than I would...They are just worried about me. I would like to be able to do more, not let

my HIV slow me down. As a man, I'd like to be able to do more physically. I want to feel strong and sometimes I don't. I guess, you know, being young and being a man, you want to feel healthy. You don't want to feel like you can't do everything you want to, so that has been difficult. (24-year-old Puerto-Rican and Black MSM)

While three women did indicate that their HIV status contributed to threats to perceived competency and contribution in the realms of employment or education, female participants were much more likely to report threats around their ability as caregivers. All but one of the women interviewed spoke to caregiving as an expectation or role that is attributed to them as women. Female participants' responses included descriptions of caregiving as both an imposed responsibility:

Being a woman, you're expected to be a certain way. Like, I have had to take care of my daughter all by myself. And I am glad to do it, but I don't think men feel that same responsibility...you just have more things to think about. Like how you dress and talk. (51-year-old Black WSM)

Women's responses also included perceptions of caregiving as an innate female value and skill:

"I think [women] just care more. We are caregivers and nurturers. We look out for people. It's in our nature. (38-year-old Black WSM)

Fifty-six percent of female participants, and 0% of male participants, indicated that being HIV positive posed threat to their role as caregivers due to HIV symptoms, treatment, or stigma. For example, some women described how HIV symptoms interfere with their ability to care for their children or families. After being asked how being HIV positive impacts her role as a mother, one participant shared the following:

...there are days when I'm feeling sick 'cause of the medications or because of the virus and I feel like I can't do what I need to do for my family. Like being able to take care of my grandchildren or cook for my family. I mean, they are good about it. They aren't scared of, like, getting the disease or nothing. So it's not that. It's, uh, there are days I don't have the energy or feel too sick to cook and watch the babies. (43-year-old Black WSM)

I have my medicines and my doctors watch for me. I was really sick at first. It was hard to deal with the diarrhea and I would throw up. I felt embarrassed. I think my daughter was scared. She was just little back then. She didn't know what was going on...And because I'm sick, I can't provide for my baby the way I want. I can't take care of her as well because I can't work. I feel sick all the time...I think she wishes we had a better life. (51-year-old Black WSM)

Other descriptions indicated that women felt they were judged to a greater extent for being HIV positive based on their role as mothers or caregivers. These participants explained that because they were in charge of caring for others, they experienced stigma in the form of fear from others that they would infect those in their care as well as doubts regarding their ability to adequately fulfill their duties:

I think a lot of Black women with HIV don't want to tell anybody because we know how hard we are on ourselves. You hear Black women talking about other Black women's business, judging whether they're being moral or talking about, are you a good mother? You don't want people talking about you like that, so you just hide it...I'm a good mother. It's the best thing I've done with my life, raising my children to be good people. And back then, no way would I have told anybody because I'd worry people would think I couldn't take care of them or that somebody might try and take them away. (49-year-old Black WSM)

I take care of my [grandchildren] and people...don't think I should be allowed to take care of them...'cause I have HIV and they think I'm going to give it to them...they talk about it like I'm...dangerous or something. (54-year-old Black WSM)

Another woman shared that women are held to different standards of responsibility as a woman living with HIV. When asked if she believes people judge her more as a PLWH because she is a woman, she responded with:

Yeah, yeah I do, because you know, we are the caregivers, we're the mothers, so there is more responsibility and so, you get more people having a say about what you should do. People don't expect much from men, so they don't care what they do. (54-year-old Black WSM)

Along with noting the judgments they personally experienced based on their roles as caregivers, women also spoke to concerns of how their children would be judged and

impacted due to HIV-related stigma. Women described how they felt compelled to protect their children from experiencing judgment or discomfort as a result of having a mother who is HIV positive:

I don't want anyone to know. I see how scared they get about it. I know they'll judge me, They'll judge my daughter...They'll think we're dirty and that we'll make them sick...I'm a mom...don't no one want to hear that I've got HIV...[She doesn't know I'm HIV positive], I don't want her to worry about it. I don't want her to know. I feel like I need to keep my baby safe. I don't want her affected by it. I don't want her to miss out on friends and things in her life because I'm the one that's got it. (51-year-old Black WSM)

I want to protect my daughter...She's 18 and I always thought, when it's time I'll tell her [I'm HIV positive]. I didn't want her to have to carry the burden or maybe feel embarrassed that she has me for a mama. But she was getting older and I told her last year, or, I tried to tell her 'cause... I think she already sort of knew, 'cause when I start telling her, she just goes "I don't want to hear none of this, I don't want to hear it." So I dropped it. But I think she knows. So I just try to keep it out of her line of sight, so to speak. I make sure I don't leave my meds out when she comes over so I don't make a big deal out of it. I don't see her very much but I try not to say anything that would make her have to think about it. (40-year-old Black WSM)

Women's responses indicated that their role as caregiver or mother compounded their HIV-related stigma beliefs in that being HIV positive challenged socially constructed norms and standards of what it means to be a caregiver and due to fears of how their children and families would be impacted by their positive HIV status.

As indicated by the data, sociocultural norms that perpetuate conventional or traditional values were apparent in shaping the assumptions and judgments that made up the HIV-related stigma experiences participants described. While the impact of a specific identity was clear in many of the stigma experiences described by participants, many experiences were described as being less explicit in nature, in that participants were unable to determine which of their identities were being stigmatized.

#### Theme 4: Navigating Multiple Marginalized Identities

Forty-seven percent of participants described the process of navigating multiple marginalized identities (e.g., positive HIV status and racial minority) and indicated that HIV-related stigma, racism, anti-gay beliefs, and sexism were often difficult to discern and distinguish between. The stigma and discrimination participants described experiencing were often depicted as ambiguous interactions without explicit messages, leaving participants uncertain as to which of their identities were being stigmatized. For example, the participant quotes below describe the ambiguity around identifying the source of stigma perpetrated by others as a PLWH with multiple marginalized identities:

I mean, I've definitely experienced racism. Sometimes it is hard to know, like, if it's because I'm Black or because they just are like that. (51-year-old Black WSM)

Some of the shelters wouldn't have me...I don't know if they were afraid because I was Black or they were afraid because I was HIV positive. (40-year-old Black WSM)

Most the time, it's just a sense I get, like, how they talk or look uncomfortable around me. I don't know exactly what they're thinking, but I know they don't trust or respect me. And I don't know if it's 'cause I'm Black or gay or what. If it's the HIV, I don't know. (20-year-old Black MSM)

Several participants indicated that having multiple marginalized identities resulted in stigmatization across contexts, in that no matter the situation, they anticipated discrimination based on at least one of their identities. For example, the participant quoted below described how being Black, gay, and HIV positive left him feeling as if experiences with discrimination were inevitable:

...there is always that fear in your head that something could happen to you because you're gay or Black or both! That's three strikes against me. It definitely feels like I'm written off. If it's not because I'm Black, it's because I'm gay. And if it's not because I'm Black or gay, it's because I have HIV. (27-year-old Black MSM)

Overall, participants described the inevitability of experiencing discrimination as a person with multiple marginalized identities and spoke of the difficulty of directly addressing or processing the discrimination they faced due to the ambiguous and inexplicit nature of the experiences. When it came to the specific instances of stigma experienced by participants within interpersonal contexts, it was difficult to be definitive about which identities were being stigmatized. In other words, perpetrators of stigma did not explicitly identify the source of their behavior, but rather stigma was experienced implicitly. However, participants' descriptions of the broader sociocultural reality and processes they experienced included specific examples of how intersecting identities shaped HIV-related stigma. The intersections of identity and sociocultural processes identified by participants as impacting their experiences with HIV-related stigma are discussed below.

#### Research Question 2: How do identity constructs intersect and impact PLWH's experiences of HIV-related stigma?

A total of three parent themes emerged across the interview data that reflected the impact of intersections of race, gender, and sexual orientation on participants' experiences with HIV-related stigma. The themes that emerged from the data were Black masculinity, connectedness and empowerment, and intersectional invisibility: these themes are presented in Tables 6, 7, and 8. Participants identified ways in which gender, sexual orientation, and race intersected with sociocultural values and processes of marginalization to shape their experiences with HIV-related stigma. As the vast majority of participants identified as Black (90%), the themes generally reflect the intersection of gender, sexual orientation, and race from the perspective of people of color.

## Theme 1: Black Masculinity

Participants' responses reflected the impact of expectations around Black masculinity in shaping the meaning of being a Black MSM living with HIV. Categories arose from the data that highlighted the role of masculinity in influencing not only the form of HIV-related stigma Black MSM face, but also in shaping sexual expression and negotiation. These codes are presented in Table 6.

Expectations regarding Black Masculinity (12 participants, 63% of Black participants):

Black participants' responses reflected specific expectations around Black masculinity, which generally epitomized rigid and traditional ideas around masculinity. For example, the participant quoted below noted the expectations Black men face when asked how gender impacts HIV-related stigma:

Black women want their men strong. They wanna know they got a real man and so, I think men get it. They wanna be a real man, 'cause if you ain't, you gonna hear about it. White people don't care. They got they metrosexuals or whatever. But if you a Black man, you gotta be a real man. (51-year-old Black WSM)

The above excerpt refers to a "real man," a concept which was reflected in other participants' responses and generally referred to concepts of virility, physical strength and dominance, and heterosexuality. In fact, 53% of Black participants (100% of Black MSM) noted that homosexuality was often considered to be incongruent with definitions of masculinity:

Being a Black man, you have very strict, um, like strict guidelines about what it means to be a Black man. It involves being, like, very masculine. People don't think you can be gay and be masculine at the same time. So if you are gay and you're sleeping with men, then you're not seen as a man or, like, not a masculine man. (50-year-old Black MSM)

Black MSM indicated that their masculinity was commonly threatened via beliefs that compare gay men to women or attribute feminine qualities to MSM:

Being a man, you know, when you gay, people are like, why you wanna be a woman? Why you wanna be gay? Just because I'm gay, doesn't mean I want to be a woman. There are those who are going through that experience, want to impersonate another gender. But I think we all have a feminine side, but it's not that I'm not masculine. (56-year-old Black MSM)

And this idea that a man, if he's gay, then he's less of a man. Uh, it's seen as feminine or, uh, like, you can tell just by looking at him. (44-year-old Black MSM)

Well, I guess being a gay man, people immediately question your masculinity. And especially if you say you have HIV. So I know if I show that part of me, if I tell someone, "Hey, I'm gay and I have HIV," there are all these assumptions that people have...like I'm a faggot, like I'm basically a woman. And worse, I'm a dirty faggot. Women don't have their gender questioned in the same way if they are gay or have HIV. It's like, they don't have as much to lose. But I have to brace myself for the shit I'm going to get, either directly or passive aggressively, that basically says, "You're gross." I don't think women get as much of that. (20-year-old Black MSM)

...being a man and gay, well then you're a faggot. You're not a man anymore. Especially when you're Black. But if you're a woman and you're gay, you're not seen as any weaker. Maybe you're even seen as stronger if you're a lesbian. (35-year-old Black MSM)

Being a man, HIV or being gay, that makes you look weaker. And that's not good if you're a man. Women can be that, that's ok. But it's not ok for a man. (31-year-old Black MSM)

Black MSM participants noted that not only did their sexual orientation threaten their identity as a Black man, but that being Black compounded their experiences of anti-gay related stigma and shaped the ways in which they felt they were able to present their sexuality. For example, one factor identified by participants as contributing to rigid expectations of Black masculinity was the need to protect against additional persecution or discrimination. Participants noted that they did not have the same racial privilege White MSM experience, which meant that they could not afford to risk compounding the discrimination they face by presenting as "gay":



I think White gay men have more flexibility in how they express themselves. So they can be as out as they want or as, like, flamboyant as they want and that seen as, uh, like, it's more accepted. But if you're Black and you're a gay man, that's dangerous. So you could see a gay Black man and not know he's gay. (50-year-old Black MSM)

...my White counterparts in my support groups...they can discern a gay person by their walk or hand gestures and stuff. And African Americans, we tend to be less conspicuous about it. It's harder to tell if we're gay unless we're in full drag. More masculine men are gay than you would think. There's more pressure for African Americans to be masculine, even when you are gay. (56-year-old Black MSM)

...being Black and being gay. I don't think you can be so open about it. Like, you will see Black men that, really, they're gay. They have sex with other men, but you would never know it. White gay that are gay, they don't seem to care who knows it. They'll talk how they want, dress how they want, hold hands with who they want. But you won't see two Black men do that. No matter what they do in private, they aren't trying to come off as gay when they're around other people...You don't want to get your ass beat! It's risky, that's a risky move there!...Because you're expected as a Black man, to really be, you know, a man. There isn't room for question about that. (31-year-old Black MSM)

[As] a Black man, you got to be stronger than a White man because you don't have all that privilege and comfort. And if you talk about being gay and HIV, immediately you're seen as less of a man. So people don't talk about it...I'm too gay for Black people. As a man, you know, you're supposed to be something. Like, there is this idea of what a man is supposed to look like. And people think if you're gay, then you're not a real man. And I think that's everywhere, but especially if you're Black. (27-year-old Black MSM)

The excerpts above indicate that presenting as traditionally masculine not only served to protect participants against general anti-gay discrimination, but can also be understood as an attempt to meet expectations of masculinity and maintain a sense of belonging within the Black community. For many of the Black MSM interviewed, being considered gay risked challenging their identity as a Black man. Black participants described equating being gay with emasculation and Whiteness, characterizing the gay male prototype as a White man who is easily identifiable via effeminate mannerisms and presentation. Eighty percent of participants who identified as Black MSM described how

Black MSM distance themselves from this stereotype by presenting in a way that is congruent with expectations of Black masculinity. Their responses reflect the ways in which the label of "gay" did not feel congruent Black MSM participants' identity and sexual expression:

I don't fit the mold because I ain't one of those little metrosexual guys. I'm just a regular dude. I take care of myself. I work out...White dudes, it's different. They walk downtown and they hold hands and look at the Christmas lights downtown. Black dudes, that shit will not happen. That's too faggity for them. They just cross their arms and look at each other and treat each other like dudes. (51-year-old Black MSM)

You know, you can't tell [I'm gay] by looking at me. A lot of Black guys who are gay, you can't tell. White guys, you can tell by how they talk and dress and they're more comfortable with, you know, having people know and acting gay and even, like, doing PDA. But Black guys, you wouldn't know. (27-year-old Black MSM)

The culturally determined incongruence between homosexuality and Black masculinity was not the only contributing factor reported by participants as shaping MSM-related stigma within the Black community. Participants also noted the role of religious belief and the importance of the church as contributing to anti-gay beliefs within the Black community.

Anti-Gay Beliefs and the Black Community (12 participants, 63% of Black participants):

Black participants described how anti-gay beliefs within the Black community contributed to strict expectations of masculinity and HIV-related stigma. Not only did 70% of Black MSM participants describe their experiences with anti-gay beliefs within the Black community, 55% of Black WSM interviewed expressed sentiments and beliefs that reflected anti-gay beliefs. Black WSM participants spoke of MSM as being "deserving" of HIV or "bringing it on themselves" and referred to MSM using discrediting terms such as "sissy boy" and "homo." Given these data, it is not surprising

that Black MSM indicated that anti-gay beliefs were common within the Black community. Participants shared how anti-gay beliefs resulted in resistance within the Black community to openly discuss sexual orientation and HIV:

Because HIV is considered a manifestation of gay... [Being gay is] more taboo. Black people don't want their men being gay. And they certainly don't want to talk about HIV. (60-year-old Black MSM)

It's like I said, that Black gay men, no one cares about us. Our own people don't want to talk about being gay and what that means. There is silence around it. It's still hush hush when it comes to all that because, in the Black community, there's still a huge stigma...around being gay. (50-year-old Black MSM)

...I'm too gay for Black people...It's one of those things where, like, your family might know [you're gay], but they don't want to talk about it...there's still a lot of silence about being gay or having HIV in the Black community. (27-year-old Black MSM)

If you're gay, and you're Black, you probably aren't talking about it. Which means you aren't talking about HIV or AIDS. (35-year-old Black MSM)

African Americans, especially, are in need of education. It is needed in the African American community because of the stigma [around being gay]. African American males, I would say, they don't care [about HIV]. I see gay people as just regular people, but [in the South], it's like you were labeled. (56-year-old Black MSM)

These data mirror the process within the Black community of distancing from HIV via stigma and avoidance as a way to protect against further discrimination and emotional discomfort. For example, one participant explained that he feels the Black community is hesitant to address anti-gay beliefs out of a desire to protect the community from additional judgment:

No one is really saying, "Look, we got a problem of homophobia in our community"...it's looked down on to say that because we already get so much from outside our community. You don't want to be attacking your own...It's easier to ignore a problem than to say, "Look, this is an issue and it's hurting us." You get a lot of backlash for saying it. (44-year-old Black MSM)

This quote speaks to stigma burnout and attempts to affirm the collective group as a way to buffer against stereotype threat and maintain collective self-esteem (Reddy, 2011).

Black participants also noted the role of religion in contributing to anti-gay beliefs in the Black community. Among the Black MSM interviewed, 80% highlighted the important role of religion and the church within the Black community, with 40% speaking directly to the influence of religion on perpetuating anti-gay beliefs within the Black community. Several Black MSM described how religious teachings were often incongruent with affirmation of their identity as a MSM:

In the Black community, if you come out to your family, you might get, "Well, we love you, but we don't love your sin." There's an idea that's a moral issue and, uh, that it's a sin and you need to turn to God to address the demons." The heart of the Black community is the church. So if you're a Black gay man and you come out, uh, you're risking losing your family, your culture, everything. You stand a good chance of being rejected...I ended up leaving the church because of all the stigma and judgment. I think church is a barrier because they get hung up on the sex part of HIV. Especially in Black churches...[with] general stigma around being gay. (44-year-old Black MSM)

I'm not religious, but that's sort of rare for someone who's Black. You know, most people are part of the church and that really means something. So there's a moral judgment people make around being gay. It's more rigid. (35-year-old Black MSM)

...all the sermons, they were homophobic. So growing up, I sat there listening to all this and then we'd go home and no one would talk about it. There's a lot of churches where people come and they do the service and they go home and that's it. (50-year-old Black MSM)

As noted earlier, participants indicated that religion contributed to the concept of HIV as a punishment for "sinning" as a MSM:

I don't know how to be religious without feeling bad about myself because you're taught in the church...being gay is wrong and this disease is a righteous punishment. (31-year-old Black MSM)

There's this idea that you deserve [HIV if you're gay]. Like you're going to hell and this is just another one of God's punishments...Black people tend to be more religious, or take religion more seriously. (20-year-old Black MSM)

Other participants described difficulty reconciling their religious identities with their sexual identities:

I didn't know how to make sense of being a Christian and being gay. And that was hard enough because people have all sorts of things to say..., "You're going to hell and you nasty," All that stuff. (60-year-old Black MSM)

Being a Christian, sometimes you ask the Lord, "Why do I have the chemistry that I do? Why do I desire sexually for a man?"...I say, "Lord, if on my day of judgment you say it's wrong, then I guess I gotta go to hell." (56-year-old Black MSM)

The data indicate how Black MSM participants' sexual orientation threatened their identity as a Black man and their belongingness within the Black community. Given these findings, it is not surprising that many Black MSM spoke of the pressure to conceal their sexual identity from others.

Black MSM and Concealment of Sexual Orientation (10 participants, 53% of Black participants):

Participants described the pressure Black MSM experience to conceal their status as a MSM due to a culturally constructed incongruence between masculinity and homosexuality, as well as anti-gay stigma. Seventy percent of participants who identified as Black MSM described the pressure Black MSM experience to conceal their sexual orientation. Interestingly, the only Black MSM participants who did not speak to feeling as if they needed to keep their sexual orientation hidden at some point in their lives were the younger participants in their 20s, which may reflect a reduction of anti-gay beliefs over time. Black MSM spoke to both personal experiences with hiding their sexual orientation as well as more general cultural values that promote shame and secrecy around being a Black MSM:

So for a lot of gay men, you know, gay Black men, they feel they have to keep it secret. Because if they were to say, "I'm gay," then they aren't a man. (50-year-old Black MSM)

[I experienced] a lot of [shame]...[because of] the secrecy around being gay in the Black community. (35-year-old Black MSM)

So Black men, if they're gay...they don't want to be thought of like that. And they end up living these double lives and not talking about it because of the stigma. (44-year-old Black MSM)

You know, this Down Low thing, it's serious...Being gay is more stigmatized in the Black community. (56-year-old Black MSM)

These excerpts begin to identify the ways in which stigma related to MSM and cultural expectations of maleness and masculinity impact the sexual behaviors of Black MSM, who present publicly as heterosexual and/or do not consider themselves gay, but have sex with other men covertly. As the last participant notes, this behavior is commonly referred to as the "Down Low" (DL) (Ford, Whetten, Hall, Kaufman, & Thrasher, 2007). The DL is a distinctively Black notion that has been used to describe Black MSM who present as heterosexual as a way to protect against the consequences of homophobia or consider themselves to be too "masculine" to be gay and may equate being gay with effeminacy and Whiteness (Denizet-Lewis, 2006). Half of the participants who identified as Black MSM mentioned the DL and two spoke directly of their own experiences being on the DL. The passages below describe their experiences being on the DL and their efforts to meet cultural expectations of masculinity by engaging in public relationships with women:

At the time I was trying to be bisexual. At the time I had a girlfriend, because I was trying to appease the family. I never had no problem having sex with nobody. I did that, 'cause I was appeasing my family. My family is always like, when I gonna get some grandkids!? I got my girlfriend pregnant and it cost me 250 dollars to get rid of it. I ain't trying to be nobody's father. Nobody ever taught me how to be no father and I know how hard that shit was for me growing up with that. I ain't trying to be a father. I had three abortions and I paid for them. Sometimes it bothers me. I'm like, I could have had kids, they'd probably be 20 or 30 years-old. It was a decision that I made. It hurts still. It doesn't hurt as much as losing my dad, but it hurts. It goes back to I woulda coulda shoulda. (51-year-old Black MSM)

For a long time, I couldn't accept [I was gay]. You know, I had these feelings for men. I mean, I could have sex with a woman, but that's not what I wanted or what I would prefer. But I made myself try to put that part away. I got married, can you believe that?! And in a lot of ways, I was a good husband. We got two kids. We was married for 20 years! But I couldn't ignore, or, I couldn't not be who I was. I would tell myself to just ignore it. I wouldn't have sex with men for a while, but then I'd always go back and I would feel bad and I'd stop again and go back. I didn't tell my wife and I would just do it in secret. Maybe she knew, but she didn't say. So when I got tested and was positive, we had to have a conversation and I told her. (60-year-old Black MSM)

Both participants quoted above spoke of loss and negative consequences associated with being on the DL. The latter participant's response notes that his behavior placed both himself and his wife at risk for HIV. Other participants described how Black women are placed at risk for contracting HIV as a result of their male partner's secret sexual lives with other men:

Women over-emphasize masculinity today, because I got a lot of friend girls that constantly ask me my opinion on the men they are dating. They are reluctant to sleep with men, because they are worried they might be gay and put them at risk...so women are looking for men that are masculine so that they know they're safe. (56-year-old Black MSM)

Being a Black woman, we are more at risk. Black men, some of them, they can't be honest if they are gay and, so, you have these Black men who are sleeping with men, but have girlfriends and don't tell anyone about it because they don't want to be looked down upon. So they come home to their women and have sex and no one talks about it. (54-year-old Black WSM)

A lot of women, they get [HIV] from they husbands or boyfriends or whatever. And the husbands, a lot of them are doing what I said before. They acting like they straight and heterosexual and all that, but they be going around having sex with men and not telling anybody about it. (51-year-old Hispanic and Black WSM)

The above excerpts highlight how shame and secrecy around homosexuality shape how Black MSM participants publicly expressed their sexuality, contributing to HIV risk among Black WSM. Expectations of Black masculinity and anti-gay beliefs were identified as not only impacting disclosure decisions and sexual behaviors among

Black MSM and WSM, but also sexual negotiation and transactions among Black MSM and other MSM.

Masculinity and Sexual Negotiation among Black MSM (5 participants, 50% of Black MSM participants):

Expectations of Black masculinity and anti-gay beliefs were also apparent in shaping sexual negotiation and transactions with other men. Participants who identified as Black MSM described the rejection of a "gay" identity and seeking dominance within sexual interactions as means of asserting their masculinity and maintaining the integrity of their identity as a Black man. The data indicated that because Black masculinity is considered incongruent with homosexuality, Black MSM may seek to preserve their identity as a Black man by seeking a dominant position within sexual relations or compartmentalizing their attraction to men as "just sex", rather than a deeper or romantic interest. The participant quoted above described Black MSM who are unwilling to consider themselves "gay" or reject relationships with other men, but have sex with other men. The data describe how, by maintaining sexual dominance (e.g., being a "top" as opposed to "bottom" in regard to sex positions and roles) and rejecting the romantic aspect of relationships with other men, Black MSM retain their sense of being men in a culture that equates being gay with femininity. For example, the excerpts below illustrate how expectations of masculinity and anti-gay beliefs impact sexual negotiations and relationships between Black MSM and other men:

A lot of Black guys, they want to have sex with you, but they don't want to say, ok, hey, I'm gay. So they don't want anything beyond just sex. (35-year-old Black MSM)

Being gay and Black is different than being gay and White. Black dudes are all stuck up on, the best way I can put it is, your tops and your bottoms. Or, you stud



or you fem? They are like, most dudes, they always like, judging you as soon as you roll in. And I'm a stud dude. I might meet a Black dude, "I like you," but we have this whole trying to figure out what we're both looking for. It's a different thing. White dudes, if they like you, they like you. They ain't trying to go through the whole, "Well, you know, I'm a bottom," or, "I'm a top"...It's more rigid with the Black brothers. Because of masculinity. Last guy I was with, we were having sex and he didn't want to do nothing because it was too gay...he told me he never thought he could be with someone like me 'cause we were the same people. And I'm like, "What do you mean? We both gay, we're having a gay experience." You know, but he was like, "No man, I ain't had someone screw me before. It ain't my thing." He had these hang ups...He was gay, but he didn't want to be too gay. They don't want it to be about the passion. Black dudes are like, let me get mine and I got to go. White dudes, like, they'll be into it. They are more open about the relationship part. The sex isn't just about coming...Black dudes, they make you feel like a vessel, like they gonna use you to come and then that's it. (51-year-old Black MSM)

The data describe how Black MSM maintain the integrity of both their sexual and gender identities by adhering to sociocultural expectations around masculinity within sexual negotiations. As reflected in the latter excerpt above, several Black MSM noted differences between their interactions with White and Black MSM with regard to sexual negotiation and expression. The data indicated that Black MSM experienced White MSM to be flexible about sexual roles (i.e., more likely to accept a more submissive role), open to MSM relationships, express higher levels of HIV education, and be more willing to openly discuss HIV. For example, the participants quoted below described feeling as if White MSM have been more accepting of their HIV status and more willing to talk about HIV:

I actually think White guys don't care [that I have HIV] as much [as Black guys] or, like, they care, but still want to have sex and don't make it a big deal...One [Black] guy got angry and was, like, mad at me because I didn't tell him [I was positive] and was wasting his time or something. Like, when he found out I had HIV, I was just a waste and not even worth it. Other Black guys, they might just be like, "Nah, I'm not interested in that." They don't know what to do with it. (27-year-old Black MSM)

My friends that are gay and White, it seems like [HIV is] not such a thing for them. I mean, it's not nothing, but they are more open and like, comfortable about

talking about it. For me, I learned to be very careful about who I tell...Also dating, some guys just don't want to get involved with [me because I'm HIV positive]. And I can respect that. I don't blame them. I mean, I'm not sure I would have before all this. White guys aren't so bothered by it. They seem more open, they talk about it more. They are much less likely to say that's a deal breaker...[because] Black people don't talk about HIV. They don't want to deal with it and they don't know much about it. (20-year-old Black MSM)

I talk to White guys and they know about HIV, like, I don't have to tell them about it. They already know, like, what the meds are like, how to manage it, using protection. All that. And they know this even if they don't have HIV. Black dudes? No. Either they don't know or they aren't talking about it. So it feels more like it stays a secret. No one wants to hear about it...it's hard to get a relationship with another Black guy started...And if you do start a real conversation or, like, a connection, the Black men I date, they don't know their status and they don't want to get tested...Black guys don't want to know...because of how people respond. Like I said, you'll be outed as gay. You'll be seen as a faggot, you know, people don't want to be around that. You face losing a lot...It doesn't feel like there's a [Black MSM] community. You know, guys get together at bars or whatever to hook up, but that's it. There's no discussion about it. It's not like White gay folks who are more open about and it doesn't matter as much if people know they're gay. If you're gay, and you're Black, you probably aren't talking about it. Which means you aren't talking about HIV or AIDS. (35-year-old Black MSM)

The flexibility in sexual negotiation and openness about HIV among White MSM described above mirrors the data that suggest White MSM have more safety in presenting publicly as gay. The data indicate that White MSM have greater privilege based on their dominant racial identity and are afforded more freedom in how their sexuality is expressed.

These data speak to the ways in which Black MSM are subjected to intersections of racism, anti-gay beliefs, and expectations of masculinity and, as a result, engage in protective behaviors aimed at reducing discrimination and maintaining identity integrity as Black men. The data suggest that these processes contribute to factors related to HIV risk, such as reduced HIV education and covert sexual behaviors among Black MSM. Furthermore, the data indicate how these intersections of racism, anti-gay beliefs, and

expectations of masculinity elicit shame and reinforce rigid boundaries and expectations around sexuality and relationships among Black MSM.

Although Black MSM described ways in which they felt disconnected from the Black community or other MSM due to pressure to conceal their status based on gay-related stigma and expectations of masculinity, overall, MSM were more likely to report being connected to other MSM and PLWH as compared to the WSM interviewed. In fact, intersections of gender, race, and sexual orientation were reported by the majority of participants as impacting their sense of connectedness and, relatedly, the manner in which they made meaning of their identity as a PLWH.

## Theme 2: Connectedness and Empowerment

The data reflect the impact of gender, race, and sexual orientation on participants' reports of coping with HIV and the connections and supports available to them.

Intersections of identity were found to shape the ways in which participants made meaning of their status and described processes of empowerment and personal growth related to being HIV positive. Codes related to connectedness and empowerment are presented in Table 7.

Advocacy and Empowerment (13 participants, 62%):

Along with reports of HIV-related stigma, participants described processes of meaning making and empowerment related to their HIV status, helping them to cope with the stigma they experienced. One theme of empowerment identified by participants was involvement with HIV advocacy work. Over half of participants shared that becoming involved with advocacy helped them to cope with HIV-related stigma and find meaning in being HIV positive. Significantly more men reported being involved in HIV-related

advocacy work (83%) as compared to women (33%). In particular, Black MSM described being motivated to get involved in advocacy by their desire to reduce stigma and increase HIV awareness and education among other MSM:

I think [being HIV positive has] taught me...that there aren't Black men talking about having HIV and so, I feel like, I can be that. I can be someone who can start to talk about it in the Black community so people know about it and have someone that gets it. So in that way, I found meaning or if you want to call it that, but mostly it's about keeping people safe and reaching out so they don't feel alone. (27-year-old Black MSM)

...getting involved in [community organizations serving PLWH] and groups has helped me to feel like I'm doing something more, like I am doing something that matters. I guess it feels good to try and help in a situation that tends to affect gay men more. As a gay man, I want to be able to help with that. (24-year-old Puerto Rican and Black MSM)

I work in HIV advocacy work...I work against the stigma. I lived it, I know how it can be. I'm lucky. I do what I love. I do something that matters. It's based in my own mistakes and my own life. I feel good about that. I can't say I'm glad I have HIV. But I know that it led me here. I decided to use it for good. Because it is what it is. (50-year-old Black MSM)

As the latter excerpt demonstrates, several MSM participants spoke directly to the hope that, by getting involved in advocacy and sharing their stories, others could learn from their past "mistakes" and reduce their risk for contracting HIV or get connected with services:

I try to be a role model, or I don't know, it feels weird to call myself that, but like, someone for younger people to look up to. I see these young guys making the same mistakes I made and I don't want them to have to learn the hard way. So I try to be open about it and talk about, you know, keep yourself safe! Be careful! Because you don't have a lot of Black men, you know, Black gay men talking about it. So I hope that I can start the conversation and people will feel like they get some information. (35-year-old Black MSM)

I don't mind sharing my story with people because if they hear my story, there may be something they can get out of it that will help them along the way, so they don't make some of the mistakes I have made. (61-year-old Black WSM)

Well, I work in HIV advocacy, getting young men tested and doing outreach in the community, stuff like that. It's important work. It feels meaningful. I feel like I'm making a difference. I didn't feel like that before, when, uh, you know working in corporate America you just don't get that same feeling. Being positive is what pushed me in that direction. Who knows where I'd be if, uh, I hadn't gotten it. I can't say I'm glad to have it. But the truth is, it led me here to a place where I'm doing some good and trying to use my story to help young men be safe. It's personal for me, 'cause the men I work with, they're the same age I was when I got infected...I was angry. I was sad...it took me a bit to figure out what to do with myself and I have to say there are some good things to come of this...The work I do in prevention and outreach. I think that's what really saved my life (laughs)! Of course the meds and all that, but I think, uh, finding my purpose has been so big in this whole process. I'm thankful that I found a way to use my experience to make a difference. (44-year-old Black MSM)

The latter exemplar above notes how advocacy helped some participants to make meaning of their HIV status by imbuing a sense of purpose to their HIV status through social contribution. As described in the below excerpts, MSM participants also indicated that engagement in advocacy facilitated connection to social supports and HIV-related services:

My doctor, she was really worried about me. She noticed I wasn't doing so good. And she told me, "You got to get some support. You got to get connected with people." So she told me to go to [community agency] and I started to talk to them about what sort of services were available. So I joined some groups and started volunteering. They were the first people that weren't doctors that I told. (35-year-old Black MSM)

It helped to meet other guys who have HIV [through advocacy and support groups]. They kept telling me, "This could happen to anyone. It happens. Learn from it and live your life." And it sunk in after a while. I'm so glad I have them and that I got involved like I did. I think that really helps. (20-year-old Black MSM)

...I feel supported [living in this city]...there is more opportunity...support groups, more services. It's easier to get connected to other people who have HIV. You can go to the support groups and meet other people who are comfortable in their skin, with 30 or 40 people in these groups, rather than six or seven [where I used to live]. It's good to know people who are in the same situation. (56-year-old Black MSM)

These exemplars speak to the role of connecting with other PLWH in providing experiences of affirmation, understanding, and support among PLWH, making the finding that only 33% of WSM reported being involved in advocacy or connected to HIV-related support services particularly salient. The women that did report engagement in advocacy and services indicated that they experienced similar benefits as those reported by MSM, such as social support and affirmation:

I work part time with [non-profit organization providing HIV-related services] so it's good (laughs)! Everybody is real comfortable talking about HIV, they have knowledge about it, so I feel like I can be myself and other people can be themselves. It's a positive environment. (49-year-old Black WSM)

I go to support groups and we all come up with the same situations we are facing. We are all people; we understand each other and know what we go through. (61-year-old Black WSM)

WSM participants described challenging stigma and empowering themselves within the contexts of personal relationships with friends and family. The data indicated that participants found meaning related to their HIV status in terms of authenticity and connection within interpersonal relationships:

You know my sister, she says, "Why do you have to tell? Why do you have to talk about it?" I say the truth will set you free. How can you act one way or say one thing and then actually be another thing? I want people to accept me for who I am. (61-year-old Black WSM)

I want to be strong for my children and they children. I want them to see [HIV] doesn't bring me down, that I got this. I want them knowing so that they can be strong too. (43-year-old Black WSM)

I am thankful to God and to my family because they are my supports. If you have God and people that love you, you don't need much else. They don't judge me and they stood by me through everything. I don't have to cover anything up, I can be real. (38-year-old Black WSM)

Although women were more likely to describe making meaning of their HIV within the context of relationships with friends and family as opposed to involvement in

advocacy work, they were also more likely to report a dearth of HIV-related support from others. In particular, women were more likely to report feeling disconnected from other PLWH and lack of HIV-related support.

Connectedness and Social Support (15 participants, 71%):

Differences by gender and sexual orientation were apparent in participants' reports of perceived support and sense of feeling connected to the broader HIV community.

Overall, women described feeling less connected to other PLWH and HIV-related supports and services. For example, while more MSM reported experiencing stigma from family (58%) or friends (42%) as compared to WSM (33% and 11% respectively), MSM were also more likely to report feeling connected to other PLWH or MSM. After aggregating all codes related to reports of HIV-related support, analysis indicated that 83% of MSM and 56% of WSM reported receiving HIV-related support from others. Relatedly, 33% of WSM stated that they were not connected with other women living with HIV as opposed to only five percent of MSM who reported not feeling connected to other MSM living with HIV.

Although approximately half of the women interviewed described receiving at least some support related to being HIV positive, WSM were more likely than MSM participants to include descriptions of feeling alone or unsupported in their interviews. Fifty-six percent of WSM participants, as compared to 33% of MSM, reported feeling disconnected and desiring more support from others. WSM participants' accounts of feeling disconnected included descriptions of non-disclosure of their HIV status, lack of relationships with other women living with HIV, and feeling as if they must rely on themselves:

I haven't told anyone [I'm HIV positive]...Nobody. I think most families would have a problem with it. I can't imagine anyone being ok with it. I feel scared a lot of the time. I worry about being around for my daughter. I don't know who will be able to take care of her. And no one knows what's happening really, so I can't ask for help...I don't know where we're all at! I don't know nobody else, or, I mean, I don't know any other Black woman who is HIV positive. Can you believe that! (51-year-old Black WSM)

I learned you gotta rely on you. Not nobody else. Your man not gonna be there. Your family might not even be there. Even your own children. You got you. And you got God. And that's it. That's all you have. So you focus on that and you let go of the rest. (42-year-old Black WSM)

I know [of a community agency that] can help people with rides to doctors or the store or whatever. They help people with HIV and get them support and I could use some support. I could really use that. But I don't want someone coming around regular like that. In my neighborhood, everybody knows what everybody else is up to. I can't risk having everybody wondering why someone is coming by every few weeks. (40-year-old Black WSM)

The women interviewed indicated that lack of connection with other PLWH contributed to the dearth of support and distress they experienced:

I didn't know anybody else who had HIV, except the man I got it from. And I wasn't wanting to talk to him. (38-year-old Black WSM)

...in some ways [being a woman] helps, like, people don't judge me like I think they would someone who was gay or does drugs. But also, sometimes I feel alone because I don't know anyone else who has HIV and the people in the groups, they were all gay men and I didn't really feel comfortable. So, you know....there isn't really people for me to talk about having HIV or who can relate to it. (54-year-old Black WSM)

Participants who identified as MSM were more likely to describe feeling supported in managing their HIV than the WSM interviewed. As noted earlier, 83% of MSM participants reported being currently engaged in advocacy and/or support groups at the time of the interview while only 33% of WSM interviewed reported the same. In fact, two participants who identified as MSM spoke of their sense that women living with HIV have less access to supports and resources as compared to MSM living with HIV:



Well, there's the extra shit you get being gay that a woman doesn't have. But I also think that, it seems like Black women, they don't have the same resources that I have being a gay man. Because like I said, the gay community talks about HIV more, but the Black community in general, they aren't talking about that. So Black women would probably feel more alone or not have the information they need. I don't know. (27-year-old Black MSM)

I know in the groups, to support people who have HIV, those groups are mostly...men. There aren't a lot of women, so I don't know who [women] talk to...or if they...don't get HIV as much. But I don't see too many women who have HIV talking about it. (60-year-old Black MSM)

These excerpts suggest that the needs of Black women living with HIV are not addressed within the Black community and by broader HIV-related efforts and services in general, creating barriers to accessing services and supports among Black women living with HIV. These findings are particularly concerning given participants' descriptions of the importance of being connected to other PLWH and other affirming communities in feeling supported and understood regarding their HIV status. For example, 58% of MSM participants shared that, while they experienced stigma and rejection from family or society, they had found acceptance and support within the gay community:

My step-brother was awful after he found out and ran his mouth to everyone. He told everyone I had HIV. So you just have to be careful about who you tell, because I wanted it to be mine to tell...We've all had gay friends growing up. My friends were already accepting of it, so I didn't really have to explain anything. It didn't change anything because being positive doesn't change who I am...My friends make up for how my family has been. And my spouse is my best friend, so I have a lot of support. I mean, my family already judged me for being gay, so after I found out I had HIV, I felt even more like I needed people who loved me. (31-year-old White MSM)

The people I hang out with get it, I don't have to hide myself from them. I take time to educate others and choose others that are understanding and supportive. And there's a lot of other people out there like me [who have HIV and are gay]...in group and volunteering. I don't feel alone because I know they get it and understand. I try not to be around people who would judge me differently. I really don't have time for that....Going to groups helped, case workers, doctors, and other group members who have been through it already were really supportive. (24-year-old Puerto Rican and Black MSM)

...people know I'm HIV positive...the place I work now is a gay bar, so they know and everyone is supportive and they don't care. But before, I was working at another bar and there is no way I would have told them...I think being younger and gay means that we have more access to information, like, we know more about it and know how to talk about it. (27-year-old Black MSM)

You know, my family and my close friends, they've known from the beginning that I have HIV. Even being gay, my family knew about that before I even knew I was positive. But I don't put it out there for just anyone because I know how people tend to think about it...There's people who have reactions or judgments that, uh, you know, I know they don't approve. Mostly when I first came out, that happened. The ones who walked away from me, uh, it's good in a way because then you know who your true friends are. You know the people who are going to stick by you. I don't take it personal cause they just don't know better...I already had a lot of support from [the gay] community, uh, my close friends and family after I came out as gay. They were really supportive so when I found out I was positive, I felt comfortable telling them about it. I think the broader community, you know, uh, that's who has issue with it. (40-year-old Black MSM)

As the above exemplars indicate, participants who identified as MSM described looking to the gay community as a source of support in coping with HIV and HIV-related stigma. Participants' responses also indicated that, because the HIV epidemic was first noted among MSM, they experienced the gay community as more familiar and understanding regarding HIV as compared to the general public:

I looked for people who knew what to expect and how to help myself. Like I said, being in the gay community, HIV is already talked about, so I already had an idea of what to do. (24-year-old Puerto Rican and Black MSM)

As the above exemplar indicates, the MSM interviewed described how membership within the gay community allowed them access to a group that is familiar with HIV and, therefore, less likely to engage in HIV-related stigma. The WSM interviewed, however, did not belong to such a group or community. The responses of WSM indicated that lack of connection with other PLWH not only limited their access to HIV-related supports, but also impacted the extent to which WSM identified with other PLWH in general.

Othering (7 participants, 33%):

Gender and sexual orientation were found to impact the extent to which participants identified with the broader community of PLWH. Several participants distinguished themselves and the meaning of their HIV status from that of other PLWH based on beliefs around what behaviors are “deserving” of HIV. Participant responses indicated that different risk behaviors and transmission modes elicit differing amounts of blame, even among PLWH themselves. As such, several participants noted how their personal identity and context of transmission were incongruent with the stereotypes of PLWH based on HIV-related stigma beliefs:

...I think people think of gay men or drug addicts or something. They aren't expecting me, you know, a grandma and someone who is...motherly. People don't expect it...people don't judge me like I think they would someone who was gay or does drugs...The people that know how I got it...they know I was a victim. (54-year-old Black WSM)

...when I explain the situation, they're sorry. They say, "Oh you poor thing!" The whole way of talking changes. And I be like, "Oh, but when you thought I was getting high and getting HIV from other dudes, you don't want nothing to do with me!"...It goes from, "Oh you dirty!" To, "Oh, poor you!" (42-year old Black WSM)

As these excerpts indicate, the HIV-related stigma participants experienced was buffered by clarifying that they had not acted in a way to “deserve” HIV, therefore shifting others’ responses from blame to sympathy. Fifty-six percent of WSM, as compared to 17% of MSM, spoke of how they were not at fault for being HIV positive. While several of these participants simply clarified their own personal context around being infected, 38% of WSM actively expressed blame toward other PLWH who are “deserving” of HIV because they engaged in IDU, casual sex, sex work, or are MSM.

This process of separating oneself as distinct and different from others is referred to as “othering” (Weis, 1995) and can be understood more simply as the mentality of

"me" versus "them." In the context of this data, the process of othering was reflected in how these women distinguished the meaning of their HIV status (e.g., "unfair") from that of other PLWH who "deserved" it. The responses of these women indicated that they had seen themselves as living in a way that was congruent with sociocultural norms and moral standards (e.g., heterosexual relationship, monogamous, did not use drugs) and, therefore, had done nothing to justify being "punished" with HIV:

I don't act like that. I'm not doing anything to get in trouble. I never did... [People who use drugs] bring [HIV] on themselves. People make bad decisions; they got to deal with what happens. (51-year-old Black WSM)

I'm mad about it! I didn't ask for this. I didn't do nothing to deserve this except fulfill my role as a wife, but it don't matter...I wasn't doing what these girls do today...I see these young girls and they're going around not respecting themselves, putting themselves at risk. That's something I don't mess with...they don't take care of themselves and be going off with whichever man pays attention to them...[Referring to MSM] God made woman for man, he didn't make no man for a man. That's not how that is. So I don't mess with that...Like I said, I didn't do nothing to deserve this. They living their life of sin and asking for it. You go against God, you asking for it. I was doing right by my family and because of my husband's sins, because he went against God, I got it. That's my burden to bear, but I ain't deserved it like these boys that like boys and all that nonsense...But if you gonna be gay or get high, then you asking for trouble. I wasn't asking for no trouble. It's different. (43-year-old Black WSM)

I was mad because, you know, I didn't do anything to deserve this. I was married, I was a good mother, I was living a good life following God's word...why would God do this? I'm not sleeping around. I'm not doing no drugs or nothing like that. ...[Gay men] got it by having all this sex with all these people and I didn't do nothing like that...they know what they doing. It's dangerous, so they already know...this could happen...they don't have shame about it! They just talk about it like it's just another thing. (54-year-old Black WSM)

The last two excerpts reflect an indignant anger at the unfairness of being HIV positive as a person who has lived a "good life," illustrating the belief that HIV is a punishment for breaking a perceived moral or ethical standard. As such, it seems as if "othering" may be motivated by a desire to buffer against stigma. From this perspective, "othering" can be understood as an effort to distance oneself from a stigmatized group,

much like HIV-related stigma and avoidance within the Black community was described by participants as protecting the Black community from further discrimination and distress. While othering may be motivated by a desire to protect against stigma and maintain identity integrity, it may also serve to contribute to the disconnection and lack of support WSM reported. By distinguishing themselves from other PLWH, women living with HIV may also feel isolated and experience reduced access to HIV-related supports and services.

The data indicated that conceptions of who the typical PLWH is contribute to the othering and disconnection reported by WSM participants, in that Black WSM described ways in which their racial, gender, and sexual identities were not congruent with the prototypical concept of a PLWH or those at risk for HIV. In fact, both WSM and MSM participants noted differences between their own identities and that of the perceived prototypical PLWH, which impacted their experiences with HIV-related stigma and the extent to which participants felt as if their needs and realities were reflected in the broader societal discourse on HIV dialogue.

### Theme 3: Intersectional Invisibility

The data reflected participants' experiences of feeling as if their needs as a PLWH were forgotten or ignored because their identities differed from that of the typical PLWH, which was generally defined as a gay White man. This theme can be understood from the framework of intersectional invisibility described earlier in Chapter 2: Literature Review. This notion suggests that individuals who possess multiple marginalized identities experience a higher likelihood of having their needs and perspectives neglected as compared to people with a single, or less, marginalized identity (Purdie-Vaughns &

Eibach, 2008). From this perspective, one way that dominant groups achieve power is by defining the societal standard or prototype as male (androcentrism) (Bem, 1994), White (ethnocentrism) (Sue, 1999), and heterosexual (heterocentrism) (Purdie-Vaughns & Eibach, 2008). As such, individuals who have identities that deviate from these prototypes in one dimension, such as identifying as gay (deviates from heterocentrism), will be assumed to have their other identities reflect the prototype of the other dimensions (i.e., assumed to be a White man). Due to these assumptions, individuals that deviate from these prototypes on multiple dimensions (e.g., Black MSM) are less likely to be recognized as members of their constituent groups (e.g., Black and gay communities).

Participants' responses reflected this process, in that they indicated that having multiple marginalized identities that deviated from the stereotypical (or prototypical) PLWH contributed to a sense of being forgotten or dismissed regarding their needs and experiences as a PLWH. Furthermore, participants also indicated that deviation from the identities of the typical PLWH impacted their perceptions of risk prior to being tested as well as the perceived availability and effectiveness of HIV-related supports and services. A total of three categories emerged from participants' descriptions of prototypical identities and they ways in which their own identities deviated. These codes are presented in Table 8 at the end of this chapter.

PLWH Prototype (12 participants, 63% of Black participants):

The majority of Black participants described the prototype of a PLWH as a one or more of the following: White, gay, and/or male. Other variations of the typical PLWH reported by participants included people that are "dirty" because they use substances, engage in sex work, or are "promiscuous." Forty-eight percent of total participants (40%

of MSM and 67% of WSM) indicated that their identities deviated from that of a “typical” PLWH. These reports included descriptions of how participants’ identities deviated from that of gay (White) men:

[The typical PLWH is] like gay men. You see a lot of movies like that. (51-year-old Black WSM)

You know, you think HIV and you think of a White gay guy or people think, like, a junkie or something. That wasn't me, I didn't fit that category. I don't know, it was just, really alone. (35-year-old Black MSM)

...when you think HIV, you think prostitutes and druggies and, you know dirty people. That's what they think if you Black. If you White, that's different 'cause you think of HIV and you White, it's like...some White gay boy. I'm not any of those things. (42-year-old Black WSM)

As the latter two excerpts presented above reflect, participants also described how they differed from the “typical” PLWH because they had not engaged in IDU, sex work, or “promiscuous” sex.

Participants indicated that intersectional invisibility impacted their experiences with HIV-related stigma in dynamic ways. For some, deviating from the prototypical identities of a PLWH actually buffered against HIV experiences, in that participants reported experiencing less judgment and assumptions from others based on their positive HIV status if their identities were incongruent with HIV stereotypes and preconceptions. This theme relates to the theme of “othering” described earlier, in that by disconfirming stereotypes of PLWH, participants experienced less blame related to their status. For example, the excerpt below describes how one woman’s identity as a “grandma” buffered against experiences with HIV-related stigma:

I think it surprises people. Like, they don't expect me to have HIV...I think people think of gay men or drug addicts or something. They aren't expecting me, you know, a grandma and someone who is, um, motherly. People don't expect it...in some ways it helps, like people don't judge me, like I think they would someone who was gay or does drugs. But also, sometimes I feel alone, because I don't

know anyone else who has HIV and the people in the groups, they were all gay men and I didn't really feel comfortable. So, you know...there isn't really people for me to talk about having HIV or who can relate to it. (54-year-old Black WSM)

While the woman quoted above explained that she experienced less judgment as a “motherly” woman who does not use drugs, she also indicated that her identity as a Black woman living with HIV contributed to feeling disconnected from HIV-related supports. The data indicated that intersectional invisibility was a significant factor in shaping participants’ perceptions of support, connectedness, and HIV-related services.

Intersectional Invisibility and Connectedness (8 participants, 42% of Black participants):

Almost half of the participants who identified as Black spoke specifically of feeling disconnected from their constituent groups of other PLWH or the gay community. For Black WSM, intersectional invisibility manifested in feeling disconnected from other women living with HIV and feeling alone in coping with their HIV status:

I haven't told anyone [I'm HIV positive]... And no one knows what's happening really, so I can't ask for help...I don't know where [Black women living with HIV are] all at! I don't know nobody else, or, I mean, I don't know any other Black woman who is HIV positive. Can you believe that!?! (51-year-old Black WSM)

One woman specifically noted that MSM seem to have more support than women living HIV:

I think the gays have a lot more support [than women]. It seems like that. They talk about [HIV] a lot. (51-year-old Black WSM)

This sentiment was corroborated by the following MSM’s reflection on his experience with HIV support groups:

I know in the groups, to support people who have HIV, those groups are mostly...men. There aren't a lot of women, so I don't know who [women] talk to...or if they...don't get HIV as much. But I don't see too many women who have HIV talking about it. (60-year-old Black MSM)



While MSM were less likely to report feeling disconnected from other PLWH, they did describe how deviating from the prototypical racial identity of a gay man as White resulted in feeling disconnected from, or not represented by, the larger gay community. For example, Black MSM spoke to feeling as if Black MSM are not generally included in the broader community:

It doesn't feel like there's a [Black MSM] community. You know, guys get together at bars or whatever to hook up, but that's it. (35-year-old Black MSM)

The tensions are there. Cause you have this long history of racism and how the Black community generally approaches being gay, so I think, most of the gay community is represented by White men. And as a Black gay man, I don't always feel welcome. I hear that a lot, that these gay and queer spaces, uh, they don't always feel like you're welcome as a Black gay man or woman. (44-year-old Black MSM)

As described earlier, several participants that identified as Black MSM indicated that they attributed effeminate qualities to the prototype of a White gay man and rejected the label of “gay” based on not only race, but because identifying as “gay” was incongruent with expectations of masculinity regarding their identity as a Black man:

I don't fit the mold because I ain't one of those little metrosexual guys. I'm just a regular dude. I take care of myself. I work out...White dudes, it's different. They walk downtown and they hold hands and look at the Christmas lights downtown. Black dudes, that shit will not happen. That's too faggity for them. They just cross they arms and look at each other and treat each other like dudes. (51-year-old Black MSM)

In addition to race and associations of effeminacy with gay men, other factors were noted by Black MSM as contributing to feeling as if they did not fit in with the gay community, such as age, physical appearance, and HIV status. These descriptions generally referred to ideals within the gay community that influenced MSM participants' sense of personal relevance and attractiveness and contributed to how welcome they felt

within the gay community. For example, one participant spoke to his age as being a restricting factor, in that he felt too old to be accepted by other gay men:

I went to a gay church for the first time in my life and it was ages from basically 18 to maybe 30. That was a new experience, I didn't enjoy it. I felt uncomfortable because I was the oldest. They looked at me as though I didn't matter, like I couldn't give them pertinent information, wisdom for their journey. One came and said hello, but that was it. I didn't fit in. (56-year-old Black MSM)

A younger participant quoted below spoke of the expectation within the gay community to be "fit" in response to being asked how changes in his appearance due to HIV had affected his social relationships:

The weight loss, I started to look sort of sick. I mean, I was sick, so that was embarrassing and hard to deal with. In the gay community, you're supposed to look a certain way...like really fit and take care of yourself. I felt like I couldn't really match that. (24-year-old Puerto-Rican and Black MSM)

Not only did participants describe ways in which deviation from the prototypical identities of their constituent groups (PLWH as White gay men, MSM as White) resulted in feeling disconnected from other PLWH or MSM, but also described how their identities contributed to feeling dismissed or forgotten in terms of broader societal conversations and public health approaches regarding HIV.

Intersectional Invisibility, Dominant HIV Discourse, and Perceptions of Risk (9 participants, 47% of Black participants):

Approximately half (50% of Black MSM and 33% of Black WSM) of the participants interviewed indicated that their identities rendered them invisible, forgotten, or overlooked in regard to the larger societal conversation about HIV. For example, this theme is reflected in the findings that women were less likely to report involvement in advocacy as compared to MSM, with several WSM explicitly naming the lack of other women living with HIV represented in groups and organizations as a reason why they felt

unwelcome or uncomfortable engaging in services. Women noted that HIV-related groups and services seemed to be made up of, and designed for, gay men:

Well, you know, that's who you think of when you say AIDS. That's who I ran into at the groups; it was all gay men... (54-year-old Black WSM)

Another participant spoke to feeling "forgotten" as a Black woman living with HIV:

I feel forgotten. What I mean is, first HIV was thought of as a White gay disease, you know, only the men. And then it was Black gay men. When will people think about women? We're here struggling and dying and nobody's listening. It sends the message that you don't matter. And it's hard to find your voice when nobody is listening. (49-year-old Black WSM)

A male participant quoted below spoke to the intersections of race and gender in describing his own sense of feeling ignored as a Black man living with HIV and his concern that the needs of Black women living with HIV are even more at risk of being neglected:

I feel like, as a Black man [living with HIV], I feel ignored. But I know my sisters...no one is thinking about them...No one cares about Black people. But it's even worse if you're a female. You'd think people would understand. Just today, you'd think people would be more educated. But they aren't. (50-year-old Black MSM)

MSM were more likely to speak directly of how HIV is addressed at a societal level and the ways in which their own identities as Black men deviated from the dominant narrative presented. Specifically, participants referred to the ways in which HIV risk prevention efforts depicted those at risk, noting that White gay men were presented as the target for interventions:

I mean, a lot of the time, you think of HIV and you think of a White guy. Like a White gay guy. And that's who you usually see talking about it...So I think for a lot of gay Black men, or at least for me, I wasn't really listening to the message until I found out I was positive. (27-year-old Black MSM)

In some ways, I feel more invisible to the outside community, uh, the bigger fight against HIV, in that my face is not the face you usually see when you think about HIV or risk...I think a White, affluent, gay male. That's sort of the stereotype. So, uh, you know, someone like me, or...or the young men I work with to try and get

them understanding their risk. I think part of why they don't always get it, cause the focus isn't on the Black community, even though we're more at risk here. Especially in [the South]. (44-year-old Black MSM)

Well, when it started coming out that HIV was affected gay men, or at least, especially gay men, I was just, maybe like 20 years-old? At first, I thought, it's all these White boys and I didn't think I [had] to worry. (50-year-old Black MSM)

As the excerpts above indicate, the lack of representation regarding the perspectives and needs of Black men and women within the dominant discourse on HIV not only left participants feeling dismissed as Black people living with HIV, but also impacted their perceptions of HIV risk prior to being tested.

Black MSM (40%) indicated that they had been aware of HIV risk within the gay community prior to testing positive, but had underestimated their risk due to HIV prevention messages that promoted the prototype of a PLWH as a White gay man. Several of the Black WSM interviewed (56%) indicated that they had not considered their HIV risk at all before testing positive for HIV. As alluded to in earlier sections (under Research Question 2, Theme 2: Connectedness and Empowerment, Othering), women indicated that they had not even considered HIV risk prior to testing positive because their identities as heterosexual married women were incongruent with their conception of who is at risk. For example, the following excerpt describes one female participant's shock at finding out she was HIV positive and her disbelief that it could happen to her as a married mother:

My husband, he was having gay sex and I had no idea... I didn't do nothing to deserve this! I was mad, because you know, I didn't do anything to deserve this. I was married, I was a good mother, I was living a good life following God's word. And then I find out and, you know, it was hard to believe and accept that. Like, why would God do this? (54-year-old Black WSM)

All in all, almost half of participants indicated that, because their identities deviated from that of the prototypical person at risk (White gay male), they had

underestimated, or been unaware of, their risk for HIV infection. Participant responses suggest that intersectional invisibility not only contributes to the disproportionate number of Black people affected by HIV by contributing to underestimation of HIV risk, but also reflects processes of racism and sexism that contribute to national and global disregard of HIV in the Black community. For example, one participant described how the focus on White men early on in the HIV epidemic resulting in not only Black MSM underestimating their risk, but also sent the message that Black men's lives did not matter:

You know, I was a young gay Black man ...when people started talking about HIV... it was talked about like a White gay disease...And honestly, for me, it was like, "Well thank God it isn't us for once."...because all the cases they talked about were these White men. But you know, now I know it wasn't really like that. That's just what they were focusing on. Black men were getting it from the beginning, but they didn't talk about that. So it was misleading, because in reality, Black men were at risk too, but no one was caring about that...There's less of a focus, because there's this thinking that it's a White gay man's disease. And they still think it's a gay disease. So the face of HIV, it's a White gay man. So the fact that it's hitting Black women and men, people don't get it. They think because...the proportion of people who are White with HIV, that's gone down. So people think, "Ok, we got this under control." But it's not. Black people are carrying the burden now. People don't get that. And my worry is...like, what if this isn't just about being ignorant about the problem? What if people kind of get it, but don't care, because, uh, it's affecting Black people. You know, it's bad, it's messed up. I don't want to believe that, but history and my experiences tell me that this is how the world works. So I think, yeah, people don't care. Let Black people die. That's the thinking. (50-year-old Black MSM)

As these participants' stories indicate, it was common for participants to describe how the intersections of their marginalized identities contributed to feeling neglected or ostracized by the larger systems and institutions, contributing to reduced access to prevention and treatment services and compounding experiences with HIV-related stigma.

The final exemplar presented speaks to one participant's concern regarding the relationship between racism and HIV-related stigma. As quoted below, he described his fear that HIV-related stigma is used to discount the needs of the Black community and reinforce racial social disparities:

Black people are carrying the burden now. People don't get that. And my worry is...like, what if [HIV-related stigma] isn't just about being ignorant about the problem? What if people kind of get it, but don't care, because, uh, it's affecting Black people. You know, it's bad, it's messed up. I don't want to believe that, but history and my experiences tell me that this is how the world works. So I think, yeah, people don't care. Let Black people die. That's the thinking. (50-year-old Black MSM)

To conclude, seven themes were derived from the 21 interviews conducted for the present study. While many of the participants' responses reflected overlapping themes pertaining to living with HIV, race, and gender, participants' responses reflected distinct differences in the HIV-related stigma experiences reported by MSM versus WSM. In the next chapter, these themes will be further explored in depth and implications for the findings discussed, concluding with a discussion of study limitations, strengths, and future directions.

Table 1: Participant demographics

	n (%)	M (SD)
Age		43.9 (12.53)
Race/ethnicity		
Black	17 (81)	
White	2 (9.5)	
Multiracial	2 (9.5)	
Gender		
Male	12 (57)	
Female	9 (43 )	
Sexual orientation		
WSM	9 (43 )	
MSM	12 (57)	
Years of education		13.5 (2.09)
Did not complete high school	4 (19 )	
High school or GED	5 (24 )	
Postsecondary education	12 (57 )	
Employment Status		
Disability	10 (48 )	
Social Security	1 (5 )	
Retired	1 (5 )	
Full or part time employment	9 (42 )	
Religious Affiliation		
Christian	8 (38 )	
Baptist	3 (14 )	
Episcopalian	1 (5 )	
Spiritual, but not religious	6 (29 )	
Agnostic/atheist	3 (14 )	
Years since diagnosis		14.1 (8.71)
Transmission Mode		
MSM sex	11 (52 )	
WSM sex	8 (38 )	
IDU	1 (5 )	
Uncertain	1 (5 )	
Injection drug use history	3 (14)	

Note. MSM = Men who have sex with men. WSM = Women who have sex with men.  
IDU = Injection drug use.

Table 2: Identity constructs reported by participants as salient to HIV-related stigma

Category	Total Participants (N=21) n (%)	Total MSM (n=12) n (%)	Total WSM (n=9) n (%)
Ethnicity/race Includes reports that assumptions and judgments were made about participants based on their HIV status and ethnicity. These include assumptions about sexual behaviors and substance use, as well as blame and judgment related to racism and stereotypes.	18 (86)	10 (83)	8 (89)
Gender Includes reports by participants that their gender impacted their experience with HIV-related stigma, including the impact of gender roles and expectations and sexism.	17 (81)	9 (75)	8 (89)
Sexual orientation Includes descriptions of blame and assumptions regarding HIV based on sexual orientation, such as the belief that HIV is punishment for being gay and that being gay is associated with promiscuity. Also includes experiences compounded by dual HIV- and anti-gay stigma.	12 (57)	12 (100)	0 (0)
Navigation of multiple marginalized identities Includes participants' descriptions of navigating stigma related to the intersection of multiple marginalized identities.	11 (52)	9 (75)	2(22)

Note. MSM = Men who have sex with men. WSM = Women who have sex with women.



Table 3: "Race" codes

Category	Total Black Participants (n=19) n (%)
Racism and the social and structural context of HIV Includes participants' descriptions of racism at institutional and structural levels that result in negative social and personal consequences.	19 (100)
Racism and symbolic stigma Includes participants' reports that their experiences with HIV-related stigma were compounded by racism.	13 (68)
Symbolic HIV-related stigma within the Black community Includes Black participants' reports of having experienced judgment and blame regarding their HIV status within the Black community.	17 (89)
Avoidance of HIV within the Black community Includes Black participants' descriptions of the Black community's reluctance to address HIV among Black people.	16 (84)

Table 4: “Sexual orientation” codes

Category	Total Participants (N=21) n (%)	Total MSM (n=12) n (%)	Total WSM (n=9) n (%)
	n (%)	n (%)	n (%)
HIV as punishment for being gay Includes participants' experiences of HIV-related stigma based on the belief that same-sex relationships and sexual experiences are "sinful" and HIV is punishment for being gay.	19 (90)	12 (100)	7 (78)
Religious influence Includes participants' reports of the influence of religion in reinforcing anti-gay beliefs and stigma.	7 (33)	7 (58)	0 (0)
Generational influence Includes participants' reports of the influence of generation on anti-gay beliefs and stigma.	6 (29)	4 (33)	2 (22)
Regional influence Includes participants' reports that they experienced higher levels of anti-gay discrimination and HIV-related stigma because they lived in the Southern region of the United States.	3 (14)	3 (25)	0 (0)

Note. MSM = Men who have sex with men. WSM = Women who have sex with men.

Table 5: "Gender " codes

Category	Total Participants (N=21) n (%)	Total MSM (n=12) n (%)	Total WSM (n=9) n (%)
	n (%)	n (%)	n (%)
Female sexuality and HIV-related stigma			
Includes WSM participants' descriptions of having their sexuality judged based on their HIV status.	14 (67)	5 (42)	9 (100)
Threats to perceived competency			
HIV as a threat to perceived ability or competency in providing financially, obtaining employment, or education.	11 (52)	8 (67)	3 (33)
HIV as a threat to perceived ability or competency in meeting expectations of caregiving role.	5 (24)	0 (0)	5 (56)

Note. MSM = Men who have sex with men. WSM = Women who have sex with men

Table 6: "Black masculinity" codes

Category	Total Black Participants (n=19)	Total Black MSM (n=10)	Total Black WSM (n=9)
	n (%)	n (%)	n (%)
Expectations of Black masculinity Includes participants' descriptions of the expectation that Black men present as traditionally hypermasculine.	12 (63)	10 (100)	2 (22)
Gay as incongruent with masculinity Includes participants who described underestimating their risk of HIV due to deviation from the prototypical PLWH.	10 (53)	10 (100)	0 (0)
Anti-gay beliefs within the Black community Includes Black participants who described experiences of anti-gay beliefs or endorsed anti-gay beliefs.	15 (79)	10 (100)	5 (56)
Concealment of sexual orientation Includes Black participants' descriptions of the pressure Black MSM face to keep their sexual orientation a secret	10 (53)	7 (70)	3 (33)
Black masculinity and sexual negotiation Includes Black MSM participants' descriptions of how expectations around Black masculinity shape sexual negotiations with other men.	--	5 (50)	--

Note. MSM = Men who have sex with men. WSM = Women who have sex with men.

Table 7: "Connectedness and empowerment" codes

Category	Total Participants (N=21) n (%)	Total MSM (n=12) n (%)	Total WSM (n=9) n (%)
Meaning and empowerment			
Participants who described finding meaning and empowerment through engagement in HIV-related advocacy.	13 (62)	10 (83)	3 (33)
Participants who described finding meaning and empowerment in terms of how being HIV positive positively impacted relationships with others.	6 (29)	2 (17)	4 (44)
Connectedness and Social Support			
Participants who reported receiving HIV-related support from others.	15 (71)	10 (83)	5 (56)
Participants who reported feeling disconnected and desiring more HIV-related support from others.	9 (43)	4 (33)	5 (56)
Othering			
Includes participants' descriptions of distinguishing the meaning of their own HIV status from that of other PLWH.	7 (33)	2 (17)	5 (56)

Note. MSM = Men who have sex with men. WSM = Women who have sex with men.  
PLWH = People living with HIV.

Table 8: "Intersectional invisibility" codes derived from Black participants' responses

Category	Total Black Participants (n=19)	Total Black MSM (n=10)	Total Black WSM (n=9)
	n (%)	n (%)	n (%)
PLWH Stereotype Includes participants' description of the PLWH prototype as White, gay, and/or male.	12 (63)	6 (60)	6 (66)
Deviation from the PLWH prototype Includes participants' descriptions of how their identities were different from the PLWH prototype.	10 (52)	4 (40)	6 (66)
Intersectional invisibility Includes participants' descriptions of feeling as if their perspectives and needs as PLWH were "invisible" because their identities deviated from the prototypical PLWH.	9 (47)	5 (50)	3 (33)

Note. MSM = Men who have sex with men. WSM = Women who have sex with men.

## CHAPTER 5: DISCUSSION

The present study explored the multiple ways in which intersecting identities of PLWH impact the experience of HIV-related stigma. In particular, this study served to address gaps in the HIV-related stigma literature by presenting the data from the personal perspectives of PLWH. This study is unique in that the impact of identity on HIV-related stigma experiences was not assumed by default of participant demographics, but rather participants were allowed to speak directly to how their identities impacted their experiences with HIV-related stigma.

The vast majority of existing studies examining HIV-related stigma and identity have recruited participants based on a distinct demographic variable within a general sampling frame, inferring the impact of identity on HIV-related stigma via correlation between demographic variables and stigma reports. This approach does not allow participants to fully define their own multiple and intersecting identities, nor does it examine the process of how identity impacts stigma experiences. Furthermore, most existing studies do not allow participants to describe their personal experiences with stigma, but rather assess stigma via measures that utilize Likert-scale or other pre-existing response options. As a consequence, participants' perspectives are forced into restrictive narratives or are quantified, meaning that the richness of their unique viewpoints is lost. As an alternative, this study examined how PLWH defined their own

identities and how these identities shaped their experiences with HIV-related stigma. In order to explore these important issues, interviews were conducted with 21 PLWH.

While the findings of this study should be viewed with caution given the small sample size and cross-sectional design, the data analysis yielded several themes that elucidated the impact of intersecting identities and sociocultural context on stigma experiences. Findings suggest that participants' experiences with HIV-related stigma included both commonalities and distinct differences rooted in specific identities, as well as relationships between marginalized social identities and processes of discrimination, such as sexism, racism, and heterosexism. These findings indicate that the experiences of stigma reported by participants were dynamic and perpetuated within structural and institutional systems that fortify social disparities and conventional social values.

Using an abductive approach, the data clarify the impact of intersecting identities on HIV-related stigma via three processes of particular significance: (1) The cyclical relationship between HIV-related stigma and other discriminatory processes, (2) the manner in which HIV-related stigma is enacted within the Black community, and (3) the impact of intersectional invisibility on connectedness and representation among PLWH who have multiple intersecting marginalized identities. These processes are discussed more fully below.

#### HIV-Related Stigma, Sociocultural Norms, and Social Inequality

Participants most commonly reported race, gender, and sexual orientation as salient in impacting their experiences with HIV-related stigma. The findings of this study suggest that intersections of identity impact HIV-related stigma by determining the lens from which people interpret and make meaning of a positive HIV status. The data reflect



not only the substantial influence of homophobia and heterosexism that has been evident since the earliest days of the HIV epidemic, but also the impact of racism and sexism in shaping the experiences of blame and judgment that participants experienced as PLWH. These findings are not surprising given the existing literature indicating that racism, sexism, and heterosexism have a significant impact on the well-being of PLWH (Collins, von Unger, Armbrister, 2008; Doyal, 2009; Logie, James, Tharao, & Loutfy, 2011; Loutfy et al., 2012).

#### HIV-Related Stigma and Race

The HIV-related stigma experienced by Black participants generally took the form of assumptions and judgments based on racist stereotypes that paint Black people as uneducated, drug users, promiscuous, or immoral. Participants described feeling as if they were assumed to be at fault for being HIV positive based on assumptions about their substance use or sexual behaviors because of their race. These findings are consistent with the literature indicating a significant association between HIV-related stigma, sexism, and racism (Logie, James, Tharao, & Loutfy, 2013) and higher rates of HIV-related stigma reported among Black PLWH as compared to White PLWH (Emlet, 2007; Loutfy et al., 2012). Participants described how stereotypes were not only inherent in the judgments they experienced as PLWH, but also indicated that their HIV status was interpreted as confirmation of racial stereotypes. This reflected how HIV-related stigma enforces stereotypes that exploit marginalized groups in order to preserve power differentials between those who stigmatize and those who are stigmatized (Hatzenbuehler, Phelan, & Link, 2013).

The impact of race on HIV-related stigma is of particular importance given the disproportionately large number of Black people who are impacted by HIV. Although only 13% of the United States population are Black (U.S. Census Bureau, 2014), Black people make up 44% of new HIV cases and 41% of total PLWH in the United States as of 2014 (CDC, 2016a). Among MSM and people who have engaged in IDU who are HIV positive, Black people make up the majority of cases (CDC, 2003; CDC, 2016b; Kral, Bluthenthal, Booth, & Watters, 1998). These racial disparities in HIV infection are not fully explained by differences in individual risk behaviors, as the literature consistently indicates that Black people report less risky drug use and sexual behaviors than White people (Aldworth, 2009; Anderson, 2003; Belzer et al., 2001; Ellickson & Morton, 1999; Fuller et al., 2002; Holtzman, Bland, Lansky, & Mack, 2001; Kral, Lorvick, & Edlin, 2000). Existing data indicate that structural and contextual factors, such as poverty and incarceration impact HIV infection in the Black community by contributing to a highly stressful social environment that does not support prioritization of health issues (Adimora et al., 2006; Webster & Lane, 2006).

#### HIV-Related Stigma and MSM

In the same way that racist stereotypes seemed to influence others' perceptions of Black PLWH, homophobia and heterosexism were inherent in the experiences of stigma reported by MSM. The findings of this study suggest that anti-gay beliefs and conventional sociocultural norms regarding sexuality and gender contribute to beliefs that HIV is a punishment or natural consequence of "sinning." Furthermore, the data indicated that anti-gay beliefs were reflected in disparaging stereotypes of gay men as being associated with drug use, promiscuity, or "perversion." Some participants expressed

frustration and embarrassment about being HIV-positive, explaining that they feared that being HIV positive would lend credence to MSM-related stigma and reinforce anti-gay beliefs that paint MSM as immoral, unnatural, or promiscuous.

The data reflect sociocultural beliefs and values at a macrosystem level that depict the sexuality of MSM as immoral and threatening to traditional values (Avery et al., 2007; Craig, Martinez, & Kane, 2005). The impact of sociocultural factors on HIV-related stigma and anti-gay beliefs is further reflected in the reports of MSM participants that indicate generation, religious beliefs, and regional culture impacted the extent to which they experienced discrimination. MSM participants indicated that stigma had lessened over time with the adoption of more favorable views of same-sex relationships by society and advancements in HIV awareness and knowledge. However, MSM also indicated that religion and living in the Southern region of the United States contributed to higher levels of discrimination. These findings are consistent with existing data indicating higher levels of religiosity, political conservatism and, consequently, more conventional sexual values, in the Southern United States (Rentfrow et al., 2013).

#### HIV-Related Stigma and Women

The stories of the female interviewees further support the role of discriminatory processes and conventional sociocultural values in shaping HIV-related stigma experiences. WSM indicated that assumptions were made about their sexual history and choices based on their HIV status. These assumptions encompassed harsh judgments based on perceived transgressions of "acceptable" female sexuality that reflect restrictive gender roles, as well as stereotypes that perpetuate blame toward women. These findings are consistent with existing research indicating that women living with HIV are often

assumed to have contracted the virus through IDU, promiscuity, or prostitution, placing them in a position of blame (Sandelowski, Lambe, & Barroso, 2004). Relatedly, gender stereotypes have been found to contribute to HIV misinformation that women are disproportionately responsible for HIV transmission, resulting in discrimination against women living with HIV (van de Wouwer, 2005).

The data also reflect the role of gender stereotypes and sexism in contributing to women's vulnerability to HIV infection. For example, WSM spoke of sociocultural taboos that deter female sexual agency as barriers to sexual education and asserting safer sexual negotiation practices with partners. As one female participant noted, "If you stop having stigma around sex, then you can talk honestly about HIV and protection." Further complicating women's ability to negotiate sexual terms are power dynamics within relationships that may reduce women's agency. Lack of agency within sexual relationships not only contributes to HIV transmission risk, but is also reflected in messages of blame related to sexuality that compound women's experiences with HIV-related stigma.

The stories of the WSM interviewed included experiences of physical and emotional abuse that occurred within their relationships with men, as well as descriptions of how they had felt unable to engage in sexual negotiation, or had not even considered the need to discuss risk with their partners. Underlying these dynamics were issues of power that determined women's ability to assert their agency within relationships and sexual negotiations. As a group, women are marginalized and face restricted access to economic resources and power as compared to men. Because of their disempowered status, women may be placed in a position of dependence on male partners for economic

survival and are at greater risk for exposure to violence within relationships with men as a result of economic and social disadvantages (Amaro, 1995; West, 2004). As a result, women often lack the power and safety necessary to assert themselves and engage in effective sexual negotiation with their male partners, placing them at higher risk of HIV (Gupta, 2000).

As posited by the Theory of Gender and Power (Wingood & DiClementi, 2002), relationships between men and women are characterized by sexual divisions of labor and power, as well as differences in emotional and relational expectations (Connell, 1987; Wingood & DiClemente, 1995). These divisions exist at multiple socioecological system levels, shaping social norms, institutional policies, and experiences of discrimination and derogation among women through abuse of control. From this perspective, HIV-related stigma and traditional values that create taboos around female sexuality can be understood as forms of abuse of control, in that these processes reinforce divisions of power by framing HIV as a punishment for deviating from expectations of female sexuality (e.g., referring to a woman living with HIV as "dirty" and judging her based on assumptions around her sexual history).

Black women, in particular, face unique and amplified marginalization at the intersections of racism and sexism and experience unique sociocultural pressures that contribute to reduced agency and power within sexual relationships. For example, Black female participants described experiencing a lack of agency within sexual relationships, due to a shortage of available Black male partners related to social conditions such as economic struggle and the disproportionately high rate of incarceration of Black men.

Black WSM described how these conditions leave Black women with fewer options and, therefore, less power.

The existing literature reflects these findings, as the male to female sex ratio in Black communities is significantly low and attributed to higher mortality rates among Black men (Adimora & Schoenbach, 2005). This shortage of men places Black women at a disadvantage in negotiating mutually monogamous relationships as Black men have significantly more options for potential female partners (Aral et al., 1999). Research indicates that scarcity of Black men and adverse socioeconomic environments contribute to denser sexual networks among Black people (Adimora & Schoenbach, 2005) and significantly impacts the likelihood of engaging in risky sexual behaviors among Black women (Adimora, Schoenbach, Martinson, Donaldson, & Fullilove, 2001) and increases risk of sexually transmitted infections (Laumann & Youm, 1999).

Gender was also found to impact experiences of HIV-related stigma in shaping the threats to competency and contribution reported by participants. Men were more likely to report concerns related to HIV threatening their ability to provide financially and be gainfully employed, while women reported concerns of how being HIV positive would impact their ability (actual or perceived) to fulfill their role as caregivers. These findings are consistent with cultural and socialized gender roles that reinforce men as financial providers and physically dominant and women as nurturers and caregivers (Lindsey, 2015).

The data indicated that the impact of women's identity as a caregiver was particularly salient regarding women's experiences with HIV-related stigma. The female interviewees shared varied perspectives on their role as caregivers, including descriptions

of caregiving as "natural" and a source of empowerment and meaning, as well as a "burden" related to unequal caregiving expectations between men and women. Despite varying views on the caregiving role, almost all female interviewees described ways in which their role as caregivers compounded their experiences with HIV-related stigma. Female participants spoke of feeling higher levels of guilt, blame, and responsibility due to their roles as caregivers and fears that others might criticize their ability to fulfill their role as a caregiver based on their positive HIV status. The women interviewed also described fears around how disclosure of their HIV status would impact their children. As a result, women were more likely to conceal their status or engage in selective disclosure as a way to protect their children. These data are consistent with research indicating women living with HIV experience intensified HIV-related stigma based on their gender and capacity to bear and infect children (Sandelowski, Lambe, & Barroso, 2004) and face dual challenges of being both a caregiver and HIV positive (Hackl, Somlai, Kelly, & Kalichman, 1997). The data suggest that women's disclosure of a positive HIV status risks judgment from others based on sociocultural expectations of the female caregiver role, in that the meaning ascribed to a positive HIV status is incongruent with sociocultural values that expect female caregivers to be "wholesome."

Overall, the data indicate ways in which marginalization and discrimination impact HIV-related stigma, but also result in cumulative and interactive negative social consequences, such as economic instability, poverty, reduced personal agency, and community disintegration; all factors that have been attributed to HIV infection (Blankenship, Smoyer, Bray, & Mattocks, 2005; Fife & Mode, 1992; Stratford, Mizuno, Williams, Courtenay-Quirk, & O'Leary, 2008). Despite the evidence emphasizing the

significant role of marginalization processes and social inequality in contributing to HIV risk, HIV continues to be stigmatized and PLWH blamed and discredited based on their HIV status and racial, sexual, and gender identities. The existing literature provides insight into mechanisms that may contribute to the perpetuation of HIV-related stigma toward those most vulnerable, such as "belief in a just world" and the process of "othering."

#### Belief in a Just World

Several participants described how people with an unknown HIV status resist considering their own HIV risk by distinguishing themselves as different from PLWH and, therefore, safe. From this perspective, symbolic HIV-related stigma can be understood as a mechanism of defense, whereby others distance themselves from the fear of HIV by denying their own risk and attributing blame based on a belief that "good" things happen to "good" people and "bad" things happen to "bad" people. This notion reflects what is referred to as a belief in a just world, which posits that people receive what they deserve in life (Furnham, 2003).

The idea that the world is indiscriminate in doling out difficult and painful experiences can be emotionally and cognitively threatening, especially since most people define themselves as basically good (Taylor & Brown, 1988). By adhering to the belief that being "good" protects against negative outcomes, threat is diminished and a sense of safety is restored. Therefore, a belief in a just world is one way to mitigate the anxiety and fear that is elicited by an unfair world. From this perspective, HIV is interpreted as a deserved consequence for doing something "bad," as empathy would challenge the defense mechanisms that protect against vulnerability and fear.



A belief in a just world seems inherent in the HIV-related stigma experiences reported by participants as reflected in assignments of blame and judgment. While there is a dearth of existing research directly examining the relationship between belief in a just world and HIV-related stigma; just world beliefs have been found to be related to greater stigma toward eating disorders and obesity (Ebner, Latner, & O'Brien, 2011), as well as mental illness (Rüsch, Todd, Bodenhausen, & Corrigan, 2010). Furthermore, higher stigmatizing attitudes toward PLWH among young people in Ghana were found to be associated with reduced intentions to engage in safer sex behaviors due to reduced perceived vulnerability to HIV (Riley & Baah-Odoom, 2010), suggesting a relationship between belief in a just world and reduced perceived vulnerability. As posited by Devine, Plant, and Harrison (1999) in their review of the literature examining how social identity, ingroup-outgroup perception, and prejudice impact HIV-related stigma, HIV-related stigma is intertwined with the motivation to maintain positive social identities via processes that distinguish oneself as part of the ingroup.

### Othering

The concept of "othering" captures the mentality of "us" versus "them," and is the process of defining others as different and separate from oneself (Weis, 1995). A belief in a just world necessitates othering, as compartmentalizing consequences and people as "bad" or "good" results in a dichotomy of ingroups and outgroups. The othering inherent in HIV-related stigma serves to maintain a sense of safety and identity integrity by distinguishing the self from others who are deemed to be suffering and discredited, thereby protecting psychological defenses such as a belief in a just world.

Othering was reflected not only in the enacted HIV-related stigma that participants reported, but was also inherent in how participants distinguished themselves from other PLWH. In particular, women who had contracted HIV by having sex with their husbands distinguished the meaning of their HIV status (e.g., "unfair") from that of other PLWH who had engaged in IDU, non-monogamous sex, or identified as MSM. (e.g., "deserved"). Furthermore, participants noted that the HIV-related stigma they experienced was reduced when others understood that they had been infected in a way that mitigated blame. Participants' reports reflect the moralization of specific behaviors, in that behaviors that challenge cultural conceptions of morality (e.g., same-sex relationships, promiscuity, drug use) elicit blame, while behaviors that are congruent with dominant social values (male-female relationships, monogamy) elicit pity, dichotomizing PLWH as victims or culprits.

#### HIV-Related Stigma and Reinforcement of Marginalization

Participants' descriptions of discriminatory sociocultural processes reflect the manner in which majority groups aim to legitimize the consequences of marginalization. That is, HIV-related stigma highlights how negative outcomes among marginalized groups are framed as the result of innate deficits or personal fault, rather than consequences related to social inequity resulting from discrimination. This process reflects back to the concepts of the belief in a just world and othering described earlier, but is compounded by mechanisms of privilege at a structural level that aim to justify group-level disparities in access to resources and power.

The data reflect a positive feedback loop between HIV-related stigma and discrimination that perpetuates processes of marginalization. In other words, the meaning

attributed to HIV is determined by the worldview and interests of dominant groups. By reinforcing just world beliefs and messages of blame, HIV-related stigma serves to legitimize the very processes of discrimination that contribute to unequal social conditions, HIV risk, and marginalization. Because HIV elicits blame, open and direct acknowledgment of HIV within marginalized groups risks confirming negative stereotypes and compounding the discrimination they already face. In this way, marginalized groups are dissuaded from addressing issues related to HIV and social inequality. This relationship is represented in figure 1 below.

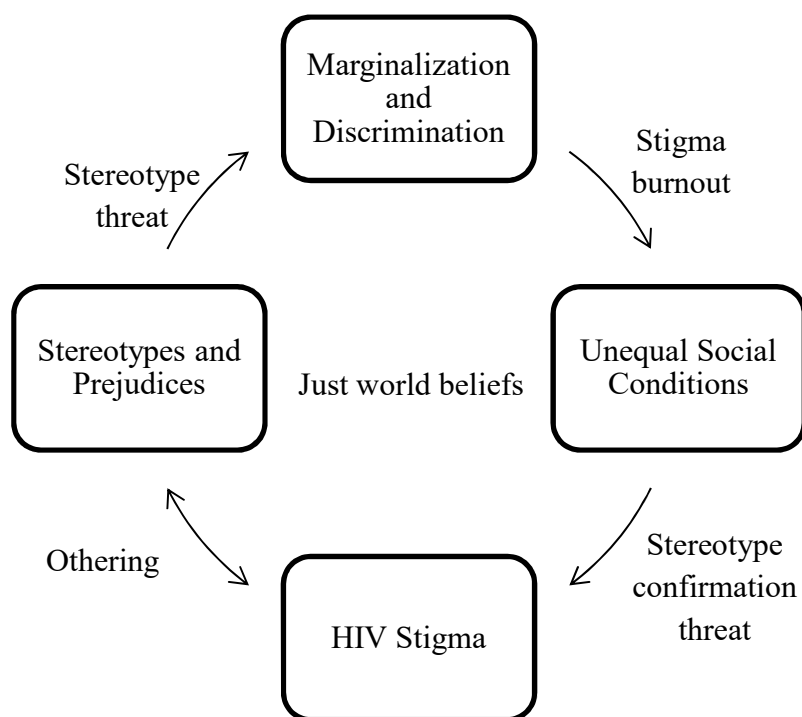


Figure 1. Model of the reinforcing cycle of marginalization and stigma.

Efforts aimed at addressing marginalization are further complicated by the often implicit and ambiguous nature of stigma and discrimination. As reported by participants, stigma experiences were often contained in subtle interpersonal interactions, rather than explicit acts of discrimination. This fits the definition of microaggressions, or routine

interpersonal exchanges that contain underlying messages that denigrate an individual based on their identity (Pierce, 1970). The perpetrators of these exchanges are generally unaware of this process (Sue, 2010) and, because the messages are subtle and covert, the individual who has been stigmatized is left to sift through the ambiguity and meaning of the event. While overt discrimination clearly harms people with marginalized identities, microaggressions have also been found to have devastating effects on those who experience them (Solórzano, Ceja, & Yosso, 2000; Sue et al., 2007). Because participants had multiple marginalized identities, included those that were concealable (e.g., HIV status, sexual orientation) and those that were not (e.g., race, gender), participants were often left wondering which identities had been discriminated against. These circumstances made it difficult for participants to directly process or address experiences of stigma, further reducing agency and power in acting against it.

The findings of this study speak to the ways in which marginalization and stigma intersect and compound across systems and result in cumulative negative consequences that reinforce group disparities in privilege and well-being. Participants' descriptions of how race, sexual orientation, and gender impacted their experiences with HIV-related stigma reflect cycles of disempowerment and marginalization that are reinforced via stereotypes and perpetuated by processes such as stereotype confirmation threat, belief in a just world, and processes of othering. In this manner, marginalized groups are told they “deserve” to be discriminated against and the responsibility of larger systems in perpetuating social inequality is dismissed.

The role of HIV-related stigma in reinforcing the cycle of social inequality and marginalization was particularly salient in Black participants' descriptions of HIV-related

stigma within the Black community. This highlights how marginalization is not only reinforced by abuse of control by those in power, but also via internalized stigma within marginalized groups themselves.

#### HIV-Related Stigma within the Black Community

The intersection of HIV- and race-related stigmas was strongly evident in Black participants' reports about their community. The majority of Black participants described their experience of HIV-related stigma from other Black people as particularly acute, indicating that stigma experiences within one's identity group may be more salient and meaningful. Overall, Black participants described a general desire of members within the Black community to distance themselves from HIV, either through active othering and blame or through reluctance to acknowledge HIV. These findings reflect existing data indicating that considerable levels of HIV-related stigma within the Black community contribute to barriers in engaging in HIV prevention and stigma reduction (Kaiser Family Foundation, 2006).

Three salient categories associated with HIV-related stigma within the Black community emerged from the data: (1) HIV-related stigma as an othering process motivated by stereotype confirmation threat, (2) HIV-related stigma in the form of avoidance resulting from “stigma burnout,” and (3) the impact of gender expectations and anti-gay beliefs on stigma within the Black community.

#### Othering of PLWH within the Black Community

HIV-related stigma as an othering process was evident in Black participants' explanations of why blame and judgement toward PLWH was particularly salient within the Black community. The data indicate that the Black community may engage in HIV-

related stigma in an effort to distance themselves from HIV so as not confirm racial stereotypes or strengthen associations between the Black community and negative labels. The moralized behaviors associated with HIV-related stigma (i.e., substance use, sex work) are also associated with systematic racism; however, these outcomes are commonly viewed as "evidence" of innate inferiority via racist stereotypes (Blake & Darling, 1994; Collins, 2000; Harris-Perry, 2011) rather than social consequences of marginalization. As noted earlier, this process is self-reinforcing, in that consequences of marginalization (e.g., poverty, incarceration, substance use) are construed by those in power as a reflection of an inherent deficiency of the groups affected (rather than the result of chronic injustice), which further perpetuates the cycle. Given this dynamic, addressing HIV within the Black community risks increasing the salience of the relationship between stigma and the Black community; thus potentially compounding existing discrimination and reinforcing racial stereotypes faced by the Black community.

#### Stigma Burnout within the Black Community

The data suggested a related process characterized by descriptions of the Black community's reluctance to openly address HIV within the community. As opposed to the active judging and othering inherent in symbolic stigma, reluctance to address HIV within the Black community was also depicted as avoidance motivated by efforts to protect already depleted mental and emotional resources. Participants indicated that the Black community already struggles with the impact of racism and may avoid addressing the impact of HIV because they lack "room for more pain." From this perspective, avoidance is not motivated by judgment, but by emotional and cognitive weariness and

reluctance to cope with additional pain. For the purposes of this study, this process is referred to as "stigma burnout."

Existing research provides support for this conjecture, as experiences of racism are associated with chronic strain (Utsey, 1998) and increased stress reactions (King, 2005), while exposure to prejudice has been found to impair cognitive functioning among Black people (Bair & Steele, 2010; Salvatore & Shelton, 2007). People of color face daily overt and covert manifestations of racism at individual, institutional, and cultural levels, resulting in psychological trauma and emotional burnout over time (Franklin, Boyd-Franklin, & Kelly, 2006). Significant cognitive and emotional resources are required to manage the effects of ongoing racism, which may limit the resources that are available to address additional sources of stress and discrimination, such as HIV-related stigma.

The data indicate that association with HIV not only risks further discrimination, but may also tax cognitive and emotional resources that are already strained as a result of experiencing long-standing racism in the Black community. The scarce existing research exploring HIV-related stigma perpetuated within communities of color reflects ambiguous results. Some studies found that people of color living with HIV report less stigma within their respective ethnic communities (Lekas, Siegel, Schrimshaw, 2006) and others suggest that HIV-related stigma is greater in communities of color, generally due to negative attitudes towards homosexuality and rigid expectations around gender (Brooks, Etzel, Hinojos, Henry, & Perez, 2005; Kalichman, 2000). The findings of this study suggest additional processes that may contribute to HIV-related stigma within communities of color, in that rejection or avoidance of HIV and PLWH may be

understood as efforts to protect group integrity and buffer against additional discrimination and distress.

#### Anti-Gay Beliefs within the Black Community

Another category that arose from the data concerning HIV-related stigma within the Black community was the impact of anti-gay beliefs on the stigma experiences of Black MSM. The data indicated the role of community norms, attitudes, and values in shaping expectations around gender roles, definitions of masculinity, and sexuality, impacting HIV-related stigma and discrimination based on sexual orientation. The church and religion were noted by participants as being particularly important within the Black community, contributing to perceptions that homosexuality is sinful and unnatural.

The church serves as a fundamental component of many Black communities (Brice & Hardy, 2015) and sexuality, especially homosexuality, is commonly proscribed or condemned by the church (Dyson, 2003; Ward, 2005). In a community where religious teachings are fundamental, the Black church plays a central role in determining cultural attitudes regarding sexuality (Laurencin, Christensen, & Taylor, 2008). Religiosity among Black people has been found to be associated with endorsement of stigma beliefs, such as believing HIV to be a punishment from God (Muturi & An, 2010).

Anti-gay beliefs and religious prescriptions around how gender and sexuality should be expressed may also serve to reinforce "hypermasculine" behaviors among Black men (both MSW and MSM) and associate HIV with sexual behaviors that are considered taboo, therefore serving as a barrier to responding to the HIV epidemic within the Black community (Ward, 2005). In fact, definitions of Black masculinity arose as particularly impactful regarding Black MSM's experiences with HIV-related stigma and



the manner in which they made meaning of their sexual orientation and engaged in sexual negotiation practices.

### Black Masculinity and MSM

Expectations around gender roles, sexuality, and definitions of masculinity emerged as salient categories in shaping the HIV-related stigma experiences of Black MSM. One of the most notable categories to emerge from the data concerned expectations regarding Black masculinity in shaping HIV disclosure decisions, MSM identity, sexual behaviors and negotiation, and presentation of sexual orientation among participants who identified as Black MSM.

Over half of Black participants spoke to the socialization of Black men to be hypermasculine and the incongruence between the conceptions of Black masculinity and a "gay" identity. Participants spoke of "gay" as White, effeminate, and "flamboyant," and Black MSM described experiences of having their maleness questioned or disparaged due to their sexual orientation. While Black MSM used "gay" to describe their sexual experiences, they made a distinction between their sexual attraction and the community they belonged to. In other words, "gay" represented a specific community or lifestyle defined by effeminacy and Whiteness, which many Black MSM participants did not feel connected to. These findings are consistent with existing qualitative data that suggests negative connotations related to a "gay" identity influence Black men in rejecting this label to describe their own behavior (Malebranche, Fields, Bryant, & Harper, 2007).

Relatedly, Black MSM participants described racial differences in presentation of sexual orientation and sexual negotiation, in that socialized definitions of Black masculinity shaped the way Black MSM expressed their sexual orientation and engaged

in various sexual roles. Several participants who identified as Black MSM explained that Black MSM are less likely to "act gay" as compared to White MSM. They described ascribing to stereotypically masculine behaviors and explained that a Black man could be gay, but "you would never know it." In contrast, participants described White MSM as having more freedom to openly express their sexual identities, as well as being more flexible in engaging in submissive sexual acts. Black MSM participants noted that, in order to affirm their masculinity and the integrity of their Black male identity, Black MSM seek dominant positions within sexual relations and reject the notion of romantic, rather than strictly sexual, relationships with other men.

While Black and White MSM both experience discrimination and stigma perpetrated by a heterocentrist society, Black MSM lack the position of power and social dominance that White MSM are afforded by their racial identity (Kenamer, Honnold, Bradford, & Hendricks, 2000). Black MSM are faced with intersections of homophobia and racism, as well as cultural norms and socioeconomic disparities that contribute to a distinctly different context for sexual disclosure and enactment. Furthermore, disclosure of a gay identity to family and the broader community risks fractured relationships and estrangement, which may be particularly difficult for Black MSM. Family and community have been identified as integral in coping with racism and discrimination among people of color (Daly, Jennings, Beckett, & Leashore, 1995; Morales 1989) and many Black MSM may not be able to afford to risk losing the support of their family and broader community (Julien & Mercer, 1991). As one participant put it, "you face losing a lot" by disclosing one's sexual orientation or HIV status as a Black MSM.

These processes are reflected in the data, as the majority of Black MSM described the pressure to conceal their sexual orientation from others within the Black community due to moral stigma, cultural expectations regarding Black masculinity, and because anti-gay beliefs compound existing experiences of racially based discrimination. As a means of adhering to cultural expectations and preserving relationships and safety, some Black MSM go on the "down low" (DL), which refers to Black men who have sex with other men but do not consider themselves gay and/or present as heterosexual in public. Two participants who identified as Black MSM spoke directly of their experiences on the DL and four participants spoke to either their partners being on the DL or DL sex among Black men in general. Sex on the DL has been cited as one of the major contributors to the increase of HIV among Black women (Millett, Malebranche, Mason, & Spikes, 2005; Montgomery, Mokotoff, Gentry, & Blair, 2004); however, the needs of Black MSM have largely been ignored within existing HIV prevention agendas (Mays, Cochran, & Zamudio, 2004) which frame HIV-related issues among MSM from a predominately White perspective and fail to consider the sociocultural context within which Black MSM exist.

The present data reflect the impact of intersecting stigmas on the identity development and behaviors of Black MSM, highlighting ways in which racism, heterosexism, and gender norms reinforce restrictive expectations around sex and relationships for Black MSM. Although Black MSM account for the largest number of new HIV infections in the United States (CDC, 2015b) and exhibit faster rates of disease progression and AIDS mortality than MSM of other races (Blair, Fleming, & Karon, 1999), there is little evidence to indicate why these disparities exist as research indicates

that risk behaviors do not account for higher rates of HIV among Black MSM (Bingham et al., 2003; Millett, Flores, Peterson, & Bakeman, 2007). The present study's data and existing research point to sociocultural processes, such as sexual networks and masculinity, physiological and psychological effects of racism and sexual prejudice, and reduced knowledge of HIV/STI status as factors that may contribute to HIV risk and stigma experiences among Black MSM (Malebranche, 2003).

### Intersectional Invisibility

Intersectional invisibility refers to the notion that possessing multiple marginalized identities results in feeling "invisible" as compared to those who identify with a single marginalized identity (Purdie-Vaughns & Eibach, 2008). As dominant cultural discourse defines the societal standard as androcentric (male), ethnocentric (White), and heterocentric (heterosexual), individuals that do not fit within these ideologies are considered to have non-prototypical identities as part of a subordinate group and experience marginalization as a result. Even among subordinate groups, members are typically assumed to reflect the dominant ideology in terms of their other constituent group identities. For example, members of the gay community are generally assumed to be White (ethnocentric) and male (androcentric). As a result, people with multiple marginalized identities (i.e., non-prototypical subordinate group members) are more likely to experience social invisibility, or the failure to be recognized as members of their constituent groups.

Non-prototypical subordinate group members may experience a mix of advantages and disadvantages. By not fitting the prototype of their respective subordinate groups, non-prototypical group members may not be as readily stigmatized or

discriminated against; however, they are also more likely to have their needs and perspectives be ignored by both their respective subordinate groups and ordinate groups who hold power. The identities that are relevant within this study's data include ethnicity, gender, sexual orientation, and seropositive status as participants reported ways in which their intersecting identities deviated from the socially constructed prototype of both PLWH and MSM.

Participants generally described the typical identity of a PLWH as that of a prototypical gay person (White gay male). Participants described how their own identities deviated from the prototype due to their race (Black participants) and/or gender (WSM). Furthermore, both Black MSM and WSM indicated that their own sexual identities deviated from the prototype in terms of sexual orientation. Although Black MSM described their sexual behaviors as gay, they did not consider their sexual identity to be congruent with a broader conception of "gay" that reflects Whiteness or a stereotypically effeminate or "flamboyant" presentation. The data indicate that deviation from this prototype resulted in consequences that could be considered as both advantageous and deleterious.

Some Black MSM noted "advantages" to deviating from the prototype of a PLWH or gay man, in that they were less likely to be identified as a MSM, resulting in lower likelihood of experiencing discrimination and stigma related to their sexual orientation or HIV status. However, the overall data reflected a sense among the Black MSM interviewed that men of color are largely neglected within the general societal conversation about HIV. Some of the Black MSM interviewed specifically spoke to underestimating their risk for contracting HIV because HIV-prevention efforts have

traditionally focused on White gay men. Black MSM also reported feeling disconnected from the broader MSM community and shared that this disconnection resulted in less available support.

The Black women interviewed echoed Black MSM's reports of feeling invisible when it came to HIV-related issues and services. Women spoke of feeling "forgotten" and were more likely to describe feeling disconnected from other PLWH, especially other women living with HIV. Furthermore, women were less likely to report being connected with HIV-related resources or being engaged in advocacy work. In fact, several women reported that they felt uncomfortable in HIV support groups that consisted mainly of men. Women also spoke to ways in which deviation from the prototypical PLWH (or people at risk for HIV) led to underestimation of their risk of contracting HIV. The women interviewed spoke of the typical PLWH as a gay man or someone who was promiscuous, used drugs, or engaged in sex work. Because these women's identities as mothers and wives deviated so significantly from conceived prototypes of PLWH, they had not considered their personal risk of contracting HIV. Several women who had contracted HIV from their husbands described ways in which deviating from the prototype of a PLWH resulted in experiencing less stigma and judgment from others, as people were less likely to blame them once they knew the transmission method had not challenged sociocultural values around heterosexuality, female sexuality, or substance use. However, women's responses also indicated that because they deviated from the prototype of a PLWH, they were also more likely to feel alienated from other PLWH and report receiving less HIV-related support.

The experiences reported by Black WSM and MSM reflect how intersecting marginalized identities contribute to feeling invisible with regard to dominant conceptions of HIV, resulting in both perceived disadvantages and advantages in terms of experiences with stigma. While Black MSM and WSM described avoiding some discrimination and stigma because their identities deviated from that of the “typical” MSM or PLWH, the data also indicated that intersectional invisibility may contribute to underestimation of HIV risk among Black men and women, barriers to receiving HIV-related services and support, and lack of representation of Black needs within HIV prevention and advocacy efforts.

Furthermore, these data reflect how those with multiple marginalized identities are often faced with competing expectations and norms in order to maintain solidarity with respective identity groups. For example, the Black MSM interviewed described incongruence between meeting the expectations of Black masculinity norms and belonging within the broader gay culture. Further exploration of this concept and its impact on HIV risk, living with HIV, and HIV-related stigma experiences is recommended.

### Summary of Findings

The findings of this study informed a conceptualization that illustrates the intersections of multiple forms of stigma, including HIV-related stigma, heterosexism, racism, and sexism, from a bioecological systems perspective (Bronfenbrenner, 1995). Taking an intersectional approach, the dynamic relationships between identity and broader social processes were examined in order to provide a theory of their impact on the experiences of discrimination and stigma among PLWH.

As the majority of participants identified as either Black MSM or Black WSM, the results generally reflect a comparison of these two groups, specifically the impact of the intersections of race, sexual orientation, and gender on the HIV-related stigma experiences of Black PLWH. Racist, sexist, and heterosexist stereotypes have infused HIV discourse since the beginning of the epidemic (Parker & Aggleton, 2003) and therefore, it is extremely difficult to clarify the distinct impact of racism, sexism, and heterosexism from the effects of HIV-related discrimination on PLWH's experiences with HIV-related stigma. However, the data gleaned from this study serve to clarify how these different forms of stigma intersect to impact the experiences of HIV-related stigma among Black PLWH.

Racism, sexism, and heterosexism shaped the assumptions others' made regarding participants' positive HIV status. In turn, HIV-related stigma served to reinforce stereotypes rooted in these discriminatory processes by framing HIV as a consequence of inherent deficiencies or as punishment for perceived deviation from socioculturally prescribed norms and values. Issues of power and privilege were inherent in participants' descriptions of HIV-related stigma, indicating that those with marginalized identities may not have the luxury of addressing stigma and discrimination explicitly. For example, individuals with dominant racial and gender identities (i.e., White men) may have more flexibility in their actions and how they present given their positions of power. Black men and women, on the other hand, are in a position where they are already discredited based on their race or gender and may not be willing to risk the additional discrimination related to failing to meet culturally constructed expectations regarding sex and gender. These processes may contribute to decisions related to HIV status disclosure, access to



services, and connectedness with other PLWH and other constituent groups. The findings of this study indicate the importance of conceptualizing and addressing HIV-related stigma as a social process that occurs within concepts of power and control (Parker & Aggleton, 2003), interacting with other discriminatory processes (e.g., racism, sexism, and heterosexism) to promote the interests of dominant groups and legitimize social inequality.

Before discussing this study's limitations and future directions, it is important to acknowledge the researcher's bias and the how this may have impacted the research process and interpretation of the findings presented above.

#### Reflexivity and Researcher Bias

In order to promote the integrity and validity of the research process, it is important to attend to the impact of researcher bias and explore the researcher's positionality regarding the themes of this study. These include the personal beliefs, values, and perspectives of the researcher that influenced the manner in which the data were collected, interpreted, and presented. Attending to researcher bias and positionality is particularly imperative in qualitative research, as outcomes are inherently viewed from the researcher's own lens, unlike quantitative processes which allow for statistical control of the effects of external variables on the outcome of interest. Researcher identity and positionality must be considered not only in terms of how bias may have influenced data analysis and interpretation, but also in terms of how the intersectional positionality of the researcher relates to the potential for reproducing inequalities and power differentials within the study process (Kerstetter, 2012; Muhammad et al., 2015). In addressing the

impact of bias and positionality, the author will transition to the use of first person pronouns in order to reflect the subjective case of the researcher's personal perspective.

#### My Personal Identity and Position of Power and Privilege

Regarding ascribed characteristics of my own identity, I identify as a cis-gender woman who is primarily attracted to people who identify as male. Although I am multiracial (White/Hispanic), I generally identify as White because others tend to characterize my racial identity to be White and aspects of Hispanic culture were not particularly salient throughout my development. I am a nondisabled person who is HIV-negative as of my last test and have no chronic physical health conditions. As a doctoral student and person who has experienced relative financial stability for the vast majority of my life, I embody a particularly privileged socioeconomic position as compared to society in general and the people who participated in the study. As such, my identities place me in a privileged position and as an "outsider" in relation to this study's participants.

My identity and positionality embody statuses gleaned from dominant group social and academic institutions. These dominant systems have historically oppressed and marginalized subordinate groups at institutional and structural levels, leaving subordinate groups in a position where they may feel the need to obscure their true thoughts and emotions and adopt norms and beliefs that reflect the dominant discourse (Scott, 1990). Given that I am an outsider in a position of privilege, participants may have felt it necessary to protect certain issues from me as a way to defend their community's identity and values. Examination of the impact of researcher identity on the research process suggests that "insiders" may have a better understanding of participants' experiences and

ability to share community knowledge and beliefs (Muhammed et al., 2015). It is likely that my identity as an outsider limited how comfortable participants felt in sharing with me and the extent to which I was able to fully appreciate their experiences.

My identity as an outsider was noted explicitly by participants twice. In one instance, a female participant and I were discussing how her racial identity impacts her experiences with HIV-related stigma and she paused to say, "I mean, it sounds like you're White, so I'm not sure how much of this is familiar to you." Another client asked me what my ethnicity was during the interview. In both cases, I indicated that I identify as White. During both instances, I acknowledged my inability to fully understand their experiences as Black people, stating that my hope for this research was to allow for better understanding of the impact of racial identity on the experiences of PLWH (both my own and others). There were also instances where participants noted our shared identity as women, particularly when discussing issues of power and agency in romantic relationships and experiences related to female sexuality and blame. These acknowledgements included statements like, "You're a woman, you know how it is," and using "we" when discussing the impact of gender on their experiences with sex-related stigma.

By explicitly acknowledging my identity and engaging participants in dialogue about the knowledge being created through the study process via member checks, I attempted to reduce the potential for reproducing power differentials and my own impact on the data collection and analysis process. However, acknowledgment and examination of my positionality and identity does not remove my impact on how participants responded to the research questions and it is inevitable that my identity and positionality

impacted how I and the participants approached the interview. As such, the data must be understood within the context of the dynamic between me and participants, in that my position as a privileged outsider is inherent in what participants chose to share and how the data has been analyzed, presented, and interpreted.

#### Experience Working with PLWH and Clinical Approach

Further impacting my approach and purpose for this research are my experiences working with PLWH in a variety of capacities over the past 10 years. I first began working with PLWH as a case manager working with women with a history of substance abuse. My role entailed providing referrals for health, education, employment, and housing resources as well as conducting rapid HIV testing for clients who were interested. I was trained from a strengths-based harm reduction approach that emphasized the detrimental impact of moralizing risk behaviors and promoted a social justice perspective. Over the last eight years I have also worked with community agencies that provide HIV-related services and engage in advocacy work as a client support provider and by providing support at community events. In fact, many of the participants I interviewed were referred to the study by providers that work at the community agency with which I had volunteered. As I had an existing favorable opinion of this agency, my bias likely impacted the way in which I asked participants about their experiences with the agency and interpreted their responses.

Furthermore, as a clinical health psychologist in training, I have worked with therapeutically clients who are HIV-positive over the past eight years. My role as a therapist has included providing emotional validation and supporting clients in building coping skills and strategies to manage the impact of HIV-stigma, as well as the

physiological symptoms and side effects related to living with the disease. As a therapist, I have been attuned to affirming the affective impact of the discrimination, alienation, and rejection that is inherent in HIV-related stigma experiences. I am particularly interested in how people make meaning of their experiences and how these meanings shape emotional well-being and relationships. This orientation is apparent in the aims of the study and also in the way in which I conducted interviews with participants.

For example, it was common for me to respond to participants' descriptions of HIV-related stigma with emotional reflection and validation. My identity as a trained clinician also seemed to have impacted participants' experiences of the interviews, in that most expressed their appreciation for the opportunity to talk about their experiences, be heard, and feel understood. This dynamic may also be reflected in the duration of the interviews, as I had initially anticipated that interviews would last approximately 45 minutes. Instead, interviews generally lasted over an hour, and I found myself having to resist the urge to continue speaking with participants even after the interview questions had been asked as there always seemed to be more valuable data to be explored regarding participants' experiences with HIV-related stigma and their intersecting identities. Following interviews, I often thought of the stories that participants shared, feeling compassion for, and appreciation of, the ways in which participants had struggled and coped with their experiences. While I believe an empathic approach that affirms the affective experiences and perspectives of participants is a valuable and valid method of doing research, it also may have contributed to a less critical exploration of alternative explanations and contributing factors in relation to participants' experiences.

As my experience of the interviews makes clear, my training and past experiences working with PLWH have impacted the lens from which I approached this work in regard to the sense of responsibility and accountability I feel toward the HIV-positive community. Relatedly, my experiences have fostered a social justice perspective that frames research as not only an exploratory process, but as an opportunity to empower marginalized groups.

#### My Values of Social Justice and Empowerment

My identity and positionality have inevitably shaped my motivations and orientation in regard to this study, perhaps most saliently in orienting my approach from a social justice worldview that is reflective of activist feminist research that aims toward a context-based portrayal of knowledge (Fine, 1994). A social justice orientation is concerned with issues of equity, self-determination, social responsibility and the manner in which resources and privilege are distributed to individuals and groups in society (Bell, 1997; Miller, 1999). This perspective emphasizes the context of institutionalized racism, sexism, and homophobia in accounting for the inequitable experiences of marginalized groups and acknowledges that the experiences and realities of people of color, women, and sexual minorities are largely dismissed or framed from the White, male, and/or heterosexual perspective within the dominant discourse.

As such, the main purpose of this study was not to come to a generalizable piece of knowledge, but to amplify the existing knowledge and wisdom of the people I interviewed, providing a platform from which their voices could be heard. My hope was that the research process would benefit participants, not only in the manner in which the results might inform HIV-related policy and services, but also via the interview process

itself. My goal was to support a reciprocal relationship between myself and participants, in that their participation not only benefitted my utilitarian motivations of knowledge production and fulfilling the requirements of a doctoral dissertation, but also resulted in an empowering, supportive, and positive experience for them as well. As posited by Pennebaker (2000), the process of telling one's story can be considered a powerful intervention, and my agenda of providing a positive and affirming experience for participants is inherent in the way I approached interviews and interpreted that data.

### Limitations and Strengths

There are several limitations inherent in this study. First, the findings should be generalized with caution due to the small sample size and cross-sectional design. Furthermore, the sample was recruited from care providers' offices and organizations offering HIV-related services. All participants reported receiving HAART and the majority reported engaging in advocacy and/or receiving HIV support services. As such, it is likely that the sample does not represent most PLWH's experiences with access to care, as existing data indicate that the majority of PLWH report low access to care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). These studies also indicate that lower access to care among PLWH and HIV-related stigma are positively associated, suggesting that the participants interviewed for the present study may reflect lower stigma levels than most PLWH experience. It should be noted, then, that even though the current sample may be more connected to services than the typical PLWH, levels of stigma reported by participants were high nonetheless. Therefore, the current data suggest that experiences of HIV-related stigma are common and extensive among PLWH.

Additionally, this study utilized an abductive approach and semi-standardized interviews in order to promote a participant-centered perspective. While this method allowed for reflexivity and empowered participants to express their personal experiences, this method design also meant that interviews were not uniform across participants. As a result, themes arose in some participant interviews, but not others based on participants responses. For example, romantic and/or sexual relationships were not specifically inquired about as part of the planned interview; however, some participants included descriptions of intimate relationships as part of their responses to the interview questions. Therefore, some categories related to relationship dynamics and sexual negotiation were not comparable across all participants.

For example, the data suggest differences between Black MSM and Black WSM living with HIV regarding intimate relationships post-diagnosis, in that Black MSM were more likely to mention dating or having sex after diagnosis while women either did not mention relationships or stated that they no longer engaged in intimate relationships. These findings suggest that gender and/or sexual orientation may interact with HIV-related stigma to impact relationships among PLWH; however, as participants were not uniformly asked about this, there was not enough data to confidently develop a clear conceptual understanding of the possible associations between the variables. While the method of the present study was intentionally designed to incorporate a breadth of variables so as to prevent restricting participants' descriptions and capture the nuances of identity intersections, the large breadth of variables and categories gleaned from the data also created challenges in developing clear, precise models to explain relationships between variables. It is recommended that future studies examine more specifically the



relationships between categories that emerged from the present study. Multiple studies, with narrower sets of variables of interest, would likely support the development of a more precise model of the impact of intersecting identities on HIV-related stigma. Specific recommendations regarding constructs of interest for further exploration are discussed below under "Future Directions."

Another limitation of the present study is the researcher's prior familiarity with the existing HIV-related stigma research and potential for bias. While strategies were employed to reduce researcher bias (e.g., member checks, reflections, and theoretical memos), it was not practically possible to eliminate all bias from the data collection and analysis processes. It is likely that the researcher's prior knowledge influenced the coding and analysis of the data, a limitation that may be reflected in the congruence between findings of the existing literature and a significant proportion of the findings of the present study. However, similarity between the current findings and previous research may also lend credence in identifying consistent relationships between identity constructs (and their related stigmas) and the experience of HIV-related stigma among PLWH.

This study also has several strengths, particularly in contributing to a sociocultural conceptualization of how intersections of identity shape HIV-related stigma experiences. This contribution is consistent with recommendations by Parker and Aggleton (2003), indicating that new investigative studies examining the social processes inherent in HIV-related stigma are imperative to developing a thorough perspective and research agenda regarding HIV-related stigma. By utilizing an intersectional approach, this study helps to clarify frameworks that explain the elaborate relationships between intersecting identities, sociocultural processes, and HIV-related stigma.

While some of the findings of this study reflect existing literature, the data also provide novel insights into how identity impacts HIV-related stigma experiences among PLWH. For example, participants' reports of race compounding their experiences of HIV-related stigma are consistent with existing data that indicate PLWH with marginalized racial identities report higher levels of stigma. These findings are generally attributed to cultural factors (such as religious beliefs and gender role expectations) and interactions with the effects of racism. Previous studies focus on the experience of HIV-related stigma among people of color in general, rather than distinguishing between the stigma enacted by one's racial or ethnic ingroup versus outgroup. The findings of the present study contribute to a more nuanced understanding of the role of race in HIV-related stigma experiences in suggesting that higher reports of HIV-related stigma among people of color living with HIV may also be associated with two distinct, but related processes. Firstly, HIV-related stigma may be internalized and enacted within communities of color as a distancing effort to buffer against additional discrimination by association. Secondly, higher levels of reported HIV-related stigma among people of color living with HIV may be related to a reduced capacity within communities of color to address HIV-related issues due to "stigma burnout," or the strain of emotional and cognitive resources due to managing chronic racism and discrimination. Further exploration of these possible processes is necessary to clarify their role in shaping Black PLWH's experiences with HIV-related stigma.

Furthermore, this study's findings suggest that multiple marginalized identities may contribute to higher levels of HIV-related stigma among PLWH not only due to intersections of stigmas and discrimination processes (e.g., such as racism, sexism, and

heterosexism), but also by rendering an individual “invisible” due to deviation from the prototypical identity of marginalized groups. While it could be argued that invisibility could protect individuals from some forms of discrimination (e.g., Black MSM report presenting in hypermasculine ways which reduce experiences with anti-gay discrimination), it may also serve to silence and disempower individuals with intersecting multiple marginalized identities. Intersectional invisibility was evident in the responses of participants that conveyed a sense of being different from other PLWH and lacking representation regarding HIV services and advocacy efforts. As the prototypical PLWH is often described as a White gay male, people of color and women may not identify with this prototype. The data suggests that deviation from this prototype could lead to outcomes such as underestimation of risk of infection, feeling ignored by the overarching HIV discourse, and a lack HIV-related services that meet the unique needs of PLWH who also have multiple marginalized identities that deviate from the dominant archetype of the typical PLWH. The data suggest that intersectional invisibility may contribute to not only HIV-related stigma experiences, but also high rates of HIV transmission and lower access to care among people of color. In other words, intersections of marginalized identities may compound stigma via layered discrimination, but also through processes that exclude people with multiple marginalized identities from broader HIV discourse and services

Perhaps the greatest strength of this study is that the data reflect the personal perspectives of PLWH, in that participants were encouraged to speak directly to the impact of their identities on their experiences with HIV. Surprisingly, the vast majority of existing research on the impact of identity on HIV-related stigma assumes the impact of identity by default of demographic sampling. In other words, most existing studies that

explore the relationship between identity and HIV-related stigma do so by purposively sampling PLWH who identify as a particular ethnicity, asking them to report their experiences with HIV-related stigma, and assuming that the reports of stigma reflect the impact of ethnicity by proxy of the sample's demographics. However, this particular approach does not clarify the social and cultural processes that might explain differences in HIV-related stigma experiences and often reduces participants' experiences to a numerical value. The present study addressed these limitations by using a participant-oriented approach that aimed to empower PLWH to define their own experiences and the impact of identity on HIV-related stigma.

In conclusion, the findings of this study contribute to a more thorough understanding of the complexity of HIV-related stigma and the interaction with other discriminatory processes such as racism, sexism, and heterosexism. While the data allow for a clearer conceptualization of how sociocultural processes interact with one another across and within ecological systems to perpetuate stigma experiences among PLWH, further research is needed to form a more comprehensive model of the impact of intersecting identities on HIV-related stigma.

#### Future Directions

As noted earlier, further exploration of the categories that emerged from the data are necessary to support the ongoing development of a comprehensive theory of the impact of intersecting identities on HIV-related stigma. Future studies should include both reflexive approaches that contribute to a comprehensive model and more systematic methods that promote precision in understanding the relationships between variables. PLWH constitute a vulnerable population of people with multiple marginalized identities.

therefore, it is of the utmost importance that research exploring issues concerning PLWH be conducted in a way that empowers participants to define their own experiences.

Studies which utilize approaches that foster equity between communities and researchers are most likely to garner data that are relevant in addressing the needs of PLWH and avoid dynamics that perpetuate disparities in power and privilege. Such approaches include community-based participatory research and narrative methods such as focus groups and in-depth interviews.

The findings of this study suggest that several categories and themes warrant further exploration. For example, a better understanding of the role of HIV stigma within the Black community would be beneficial in fully appreciating the impact of racism on community level public health issues and to aid in the development of effective public health interventions. The data suggest that HIV within the Black community is often stigmatized due to fears of confirming racist stereotypes and concerns of compounding experiences of discrimination and marginalization. However, because participants were not asked directly about stereotype confirmation threat and seronegative Black participants were not included in the study, this theory is limited to conjecture based on participants' perspectives. It is particularly important that barriers to prevention, testing, and care be explored given the salience of HIV-related stigma within the Black community and the high number of Black people impacted by HIV. By assessing the role of stereotype confirmation threat in perpetuating HIV-related stigma, future studies may assist in efforts at better meeting the public health needs of the Black community.

Another domain that requires further exploration is the concept of being on the "Down Low" (DL) among Black MSM and the impact on HIV stigma and risk.

Mainstream gay culture includes a “coming out” narrative and cultural representations of what it means to be gay often include an expectation of an outward presentation that designates a person as “gay.” This representation generally includes an open demonstration of one’s sexual orientation and/or an effeminate or flamboyant presentation. This narrative may not accurately reflect the experience of Black MSM, who assert their masculinity and racial identity by distancing themselves from the prototypical ethnocentrism of White gay culture (Denizet-Lewis, 2003). Furthermore, the prominent role of religion in the Black community and increased importance of family support among people of color in managing racial discrimination may serve to motivate Black MSM to keep their sexual orientation private. As the dominant “gay narrative” commonly paints MSM who are “in the closet” as perpetuating anti-gay beliefs and homophobia, Black MSM may be unfairly pathologized for being on the “Down Low” and the HIV-related stigma they experience compounded by not only racism and anti-gay beliefs, but also expectations around “coming out.” As such, narrative studies examining how Black MSM make meaning of their sexual identities within a sociocultural framework that considers the historical context of racism, heterosexism, and dominant gay culture are recommended.

Furthermore, issues related to power dynamics and sexual negotiation between Black men and women as they relate to HIV-related stigma and risk necessitate further attention. The findings of the current and existing studies point to the importance of sexual negotiation in combating HIV among Black WSM. Women's ability to engage in sexual negotiation is influenced not only by sociocultural sexual values, but also socio-structural factors, such as poverty and the ratio of available men to women, that

determine women's power and agency within relationships. The findings of this study that female participants were more likely to indicate that they had not sought a romantic or sexual relationship post-diagnosis suggest that HIV-related stigma further disempowers women from engaging in sexual negotiation. Studies that examine the structural, cultural, and interpersonal dynamics that contribute to women's sexual agency are needed in order to better understand HIV-risk among Black women and the impact of HIV on Black women's relationships.

The findings of this study also indicate that the extent to which the needs and perspectives of people of color are represented in existing HIV prevention efforts, advocacy, and services should be examined. The data suggest that intersectional invisibility may contribute to underestimation of HIV risk within the Black community and create barriers to treatment and accessing effective supports and services among Black PLWH. As Black people are disproportionately impacted by HIV, these findings are particularly concerning. Further research exploring the needs of Black PLWH is needed in order to provide services that effectively address HIV within the Black community.

Lastly, strengths-based studies that examine how people of color and women living with HIV challenge the processes of marginalization are needed in order to promote a less pathologizing view of the impact of HIV among marginalized people. Strengths-based approaches are also useful in guiding the development of approaches and interventions aimed at empowering PLWH and at-risk groups. Relatedly, studies that consider the sociocultural context and impact of heterosexism, and sexism on HIV-related stigma and risk are necessary to reduce HIV-related stigma. Approaches that

support social justice efforts that call for structural and institutional change will serve PLWH and advance the well-being of the entire population.

### Conclusion and Implications

This study supports the importance of conceptualizing and addressing HIV-related stigma from a bioecological perspective, taking into consideration institutional, structural, and the broader sociocultural processes that contribute to the context PLWH exist within. The findings of this study indicate that, in order to effectively reduce HIV-related stigma and address the negative consequences associated with it, we must also address long standing forms of discrimination (such as racism, sexism, and heterosexism) and the ways in which they perpetuate unequal social conditions and marginalization. Processes that serve to protect the interests of those in power are perpetuated via discrimination that occurs not only towards, but within marginalized groups. Individuals, institutions, and structures are rewarded for reinforcing androcentric, ethnocentric, and heterocentric ideals and face exclusion and punishment if they challenge such notions. In other words, not only do systems exist that reinforce the power and privilege of dominant groups, there are systems in place that discourage and undermine marginalized communities. These realities were inherent in participants' stories of HIV-related stigma and discrimination and highlight the necessity of framing identity as a sociocultural construct that is influenced by the historical and social context of exploitation, objectification, and domination. These data indicate that people of color and women have unique needs and narratives when it comes to their experiences with HIV; however, their needs may be dismissed or overlooked as a result of dominant androcentric and ethnocentric ideologies that frame HIV from a White gay male lens.



While it may be tempting to examine identity as distinct constructs in terms of clarity and ease of measurement, the findings of this study suggest that identity is intersectional and that the processes by which identity impacts individuals' experiences are interdependent and dynamic. Various forms of discrimination and stigma are not experienced by those impacted by them as distinct; rather, these experiences are generally ambiguous and compound in nature. It is this researcher's opinion that study methods and conceptualizations that treat various discrimination processes as exclusive may not capture the syndetic way in which these processes are experienced and perpetuated.

Advocates, service providers, policy makers, and clinicians working with PLWH should keep in mind the broader sociocultural context in which PLWH exist within, utilizing an ecological framework that acknowledges the impact of oppression and disparities in power and privilege on the experiences and decisions of marginalized people. Furthermore, approaches that define groups by a single identity (e.g., the Black community, women, or gay men) may not be effective in addressing the distinct needs of those who have multiple marginalized identities. Those with intersecting identities face not only societal level marginalization, but also marginalization within their respective identity groups. As such, approaches that affirm alternative cultural narratives (rather than pathologize or ignore them) and address the compounding nature of intersecting stigmas among PLWH are necessary in not only creating an accurate conceptualization of HIV-related stigma, but also in empowering PLWH, designing effective and meaningful interventions and services, and addressing disparities in transmission and access to care.

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## APPENDIX A: RECRUITMENT FLYER

### **BE A VOLUNTEER**

#### **Participate in a Confidential Research Study**

### **LIVING WITH HIV**

**If you are living with HIV, we want to hear about your experiences. Your participant could help improve the care and treatment of people living with HIV.**

**Call toll free: 1-844-884-9712**  
45-60 Minute Telephone Interview

**You will receive a \$10.00 gift card  
for your participation.**

**If you receive voice mail, please leave a number & a time when you can be reached.**

Do not leave your name (or leave your first name/alias only if someone else might answer your phone when your call is returned). We will call you back.

Your decision to participate is completely voluntary and you may decide to stop at any time during the interview. Any information you provide will be confidential. Nothing you say will be linked to your name or identity in any way. If you have questions at any time, you may contact Laura Lovato at the number above. If you have questions about your treatment as a research study participant, you may contact the Office of Research Services at 704-687-1888.

## APPENDIX B: INTERVIEW STRUCTURE

For this study, I would like to talk with you about who you are as a person, how this impacts your experience with HIV and HIV-related stigma, and anything else that you think is important when it comes to your experiences with HIV and HIV-related stigma. To help me understand this, I would like to ask you some background questions.

I'd like to begin by asking questions about your identity, or the parts of you that make up who you are and how others see you and treat you. Any questions before we begin?

1. To begin, what is your current age?

How does your age impact your experience with HIV-related stigma?\*

2. What is your ethnicity?

How does your ethnicity impact your experience with HIV-related stigma?\*

3. How do you define your gender?

How does your gender impact your experience with HIV-related stigma?\*

4. What is your sexual orientation?

How does your sexual orientation impact your experience with HIV-related stigma?\*

5. How would you describe your religious beliefs?

How do your religious beliefs impact your experience with HIV-related stigma?\*

6. What is your highest level of education you have completed?

How does your education impact your experience with HIV-related stigma?\*

7. Are you currently employed? What field do you work in?

How does your employment status impact your experience with HIV-related stigma?\*

8. When were you diagnosed with HIV?

What was it like for you when you first found out you were positive?\*

9. Do you know how you may have been infected?

How did the way you were infected impact your experience with HIV-related stigma?\*

10. Have you ever injected drugs?

(If yes) How does your history of injection drug use impact your experience with HIV-related stigma?\*

(If no) How do you think HIV-related stigma is different for people living with HIV who have a history of injecting drugs?

11. Are there other parts of your identity that play an important part in who you are and how others see you that I did not mention?

How does this identity impact your experience with HIV-related stigma?\*

12. When you tell people you are HIV positive, what sort of things do they assume about you?\*

\*Probe using Social Impact Scale Questions as well as questions examining the intersections between identities.

## APPENDIX C: SOCIAL IMPACT SCALE ALTERED TO BE HIV SPECIFIC (FIFE & WRIGHT, 2000)

Participants are asked to identify whether they strongly agree, agree, disagree, or strongly disagree with the following statements:

### Social Rejection

1. My employer/co-workers have discriminated against me because I have HIV.
2. Some people act as though I am less competent because I have HIV.
3. I feel I have been treated with less respect than usual by others because I have HIV.
4. I feel others are concerned they could “catch” my illness through contact like a handshake or eating food I prepare.
5. I feel others avoid me because I have HIV.
6. Some family members have rejected me because I have HIV.
7. I feel some friends have rejected me because of my illness.
8. I encounter embarrassing situations because I have HIV.
9. Others seem to feel awkward and tense when they are around me because I have HIV.

### Financial Security

10. I have experienced financial hardship because I am HIV positive that has affected how I feel about myself.
11. My job security has been affected because I have HIV.
12. I have experienced financial hardship because I have HIV that has affected my relationship with others.

### Internalized Shame

13. I feel others think I am to blame for having HIV.
14. I do not feel I can be open with others about having HIV.
15. I fear someone will tell others that I am HIV-positive without my permission.
16. I feel I need to keep my illness a secret.
17. I feel I am at least partially to blame for my illness.

### Social Isolation

- 18. I feel set apart from others who do not have HIV.
- 19. I have a greater need than usual for reassurance that others care about me.
- 20. I feel lonely because I have HIV.
- 21. Because I have HIV, I have a sense of being unequal in my relationships with others.
- 22. I feel less competent than I did before I found out I have HIV.
- 23. I sometimes feel useless because I have HIV.
- 24. Changes in my appearance due to having HIV have affected my social relationships.

## APPENDIX D: INFORMED CONSENT (VERBAL)



## Informed Consent for Intersectionality of Identity and HIV-Related Stigma

Hello, my name is Laura Lovato and I am a doctoral student at the University of North Carolina at Charlotte studying HIV-related stigma. When I say stigma, I'm talking about any negative or unfair beliefs others may have about people living with HIV or HIV in general. I am currently talking to people with HIV to help understand their experiences with HIV-related stigma and how their identities, such as their race, gender, sexual orientation and other identities impact their experiences with HIV-related stigma.

If you consent to this research, I will ask you about the stigma associated with HIV, how you think your race, gender, and sexual orientation impacts your experiences, and what can be done to help people living with HIV in your community. This information will help us to better understand the stigma experiences of people who are living with HIV and to plan for better HIV care.

All information you provide will be confidential. You do not need to provide your name or any information you are uncomfortable sharing. I will reimburse you with a \$ 10.00 gift certificate for your time and the telephone interview will probably take about 30 minutes to complete.

If you agree to participate, this interview will be audio-recorded. Only myself and the research team will have access to the recording. It is important for you to understand that you are a volunteer, which means you may refuse to participate at any time. You will not be penalized if you refuse to participate, nor will you lose any benefits to which you are entitled. Any information you provide will be confidential which means any information you provide will not be attached to your name or any other identifying information.

You must be over 18 years old to participate. If you have any questions, you can call this number to speak to me at any time. Also, UNC-Charlotte is eager to insure that all research participants are treated in a fair and respectful manner, and if you have any concerns or questions, you should contact the Office of Research Compliance at 704-687-1888.

Are you willing to participate in this research? Do you have time now, or shall I call you again later? Are you comfortable completing this information where you are now? (i.e. probe for confidentiality; i.e. is there someone that might listen to your answers?). Are you 18 years of age or older? (if yes, proceed) Are you HIV positive? (If yes, proceed)

(If participant agrees to informed consent, proceed with the following)....

Thank you for agreeing to be part of this study. I will be asking you questions about your experiences with HIV-related stigma and how you feel your race, gender, and sexual orientation has affected your experiences. Your participation is voluntary, so you are free to not answer any questions you are not comfortable with. But please remember, your answers are completely confidential and private. (*If participant agrees, continue*). Thank you, I will now begin audio-recording. Please let me know if you have any questions throughout the interview.

## APPENDIX E: DEBRIEFING FORM



Clinical Health Psychology

9201 University City Boulevard, Charlotte, NC 28223-0001

Dear Participant,

Thank you for very much for taking the time to answer a health study survey over the phone. This survey is part of a study conducted by Laura Lovato, a doctoral student at the University of North Carolina at Charlotte. The primary objective of the study was to better understand how identity components (such as race and gender) influence the experience of living with disease. We greatly appreciate your contribution. The enclosed gift card is reimbursement for your time.

If you have any questions about this study, you may contact Laura Lovato. UNC Charlotte is eager to insure that all research participants are treated in a fair and respectful manner. If you have any concerns or questions, you may contact the Office of Research Compliance at 704-687-1888. This research was approved by the UNC Charlotte Institutional Review Board on February 19, 2015, Protocol 15-01-08.

Laura V. Lovato

Doctoral Candidate, Clinical Health Psychology

University of North Carolina at Charlotte



## APPENDIX F: CODING FRAME

Theme	Code	Category	Description
Race	Racism and social context	Unequal social conditions	Descriptions of the impact of racism on social conditions, such as poverty and incarceration.
		Social conditions and HIV risk	Descriptions of how unequal social conditions and marginalization increase HIV risk within the Black community.
		Dismissal of racism and social conditions	Descriptions of the broader population dismissing the reality of marginalization and racism.
	Racism and symbolic stigma	Assumptions about behaviors	Assumptions about risk behaviors or mode of transmission based on race.
		Assumptions of ignorance	Assumptions that participants got HIV because they were uneducated or incompetent in some way.
		Blame	General sense of feeling blamed for being HIV positive as a result of being Black.
	Stigma within the Black community	Judgment	Judgment and stigma toward PLWH within the Black community.
		Silence and avoidance	Lack of discussion or acknowledgment of HIV within the Black community.
		Don't want to be associated	Desire not to be associated with HIV within the Black community.
		Stereotype confirmation threat	Concern that associations between HIV and the Black community could reinforce stereotypes and compound discrimination.
		Stigma burnout	Emotional and cognitive exhaustion as a result of ongoing racism and marginalization.

Sexual orientation	HIV as punishment for being gay	HIV synonymous with "gay"	Reports that society harbors strong associations between being gay and HIV positive, and vice versa. Also includes reports that coming out as HIV positive also required disclosing sexual orientation.
		HIV as natural consequence of being gay	Beliefs that HIV is inevitable for gay men, or is a natural consequence of male-male sex.
		HIV as "proof" that being gay is wrong	Beliefs that HIV among MSM is "evidence" that male-male sex is wrong or unnatural.
	Gay stereotypes	Assumptions about risk behaviors	Beliefs that gay men are sexually promiscuous, use drugs, or are in some way immoral.
Gender	Female sexuality	Assumptions of promiscuity/ blame	Reports that women living with HIV are assumed to have been promiscuous and are to blame for being infected as a result.
		Sexual double standard	Descriptions of double standards regarding expectations for acceptable male and female sexuality.
		Safer sex negotiation	Descriptions of how gender impacts women's ability to negotiate for safer sex and sense of sexual agency.
		Expectations of female sexuality	Beliefs that women should not be sexually assertive and experiences of being shamed sexually as a woman.
	Threats to perceived competency and contribution	Employment and income	Descriptions of how being HIV positive threatens perceived ability to be successfully employed and financially provide.
		Physical strength	Descriptions of how being HIV positive threatens physical strength.
		Caregiving	Descriptions of how being HIV positive threatens

			perceived ability to provide for children and family.
Navigating multiple marginalized identities		Microaggressions	Descriptions of stigma/discrimination experiences that were not explicit.
		Uncertain source of discrimination	Descriptions of not knowing which identity(ies) were being discriminated against during stigma experiences.
		Multiple marginalized identities	Descriptions of having several multiple marginalized identities and how this impacts stigma experiences.
Black masculinity	Expectations of Black masculinity	Black masculinity as hyper-masculine	Expectations that Black men fit stereotypical and conventional ideals of masculinity.
	Gay as incongruent	Gay as effeminate	"Gay" as feminine, "flamboyant," and easily perceived by others.
		White MSM vs. Black MSM	Descriptions of how White MSM present versus Black MSM.
	Anti-gay beliefs with Black community	Gay as sinning	Descriptions of the church's and religion's influence on reinforcing anti-gay beliefs within the Black community.
		Avoidance of addressing homophobia and anti-gay beliefs	Reports that the Black community avoids addressing and acknowledging homophobia.
	Concealment of sexual orientation	Don't "act" gay	Descriptions of how Black MSM's presentations do not fit stereotypes of gay men and inability to determine a Black MSM's sexuality by observing him.
		Non-disclosure of sexual orientation	Descriptions of choosing not to disclose status as a MSM due to concerns around anti-gay discrimination and/or HIV stigma.
		"Down Low"	Reports of Black MSM presenting as heterosexual in

	Sexual negotiation		general day-to-day, but having sex with other men in secret.
		Top/dominant	Reports that Black MSM seek dominant sexual roles to maintain integrity of their identity as a Black man.
		Just sex	Reports that Black MSM see their sexual orientation as "just sex," preferring to reject relationships and romantic aspects with other men.
Connectedness and empowerment	Meaning and empowerment	Advocacy	Reports of making meaning and being empowered through involvement in HIV advocacy.
		Using "mistakes" to help others	Making meaning of own status by using past to educate and support others.
		Disclosure of status to others as empowerment	Descriptions of disclosure as empowering and rewarding in the context of relationships.
	Connectedness and social support	Receipt of HIV-related support	Receiving support from others in relation to being HIV positive.
		Desire for more HIV-related support	Reports of wanting more support from others regarding being HIV positive.
		Connection with other PLWH	Reports of knowing and being connected to other PLWH.
		Disconnected from other PLWH	Feeling disconnected from or not knowing other PLWH.
	Othering	Distinguishing meaning of personal HIV status	Distinguishing the personal meaning of one's HIV status from that of other PLWH.
		Blame distinctions	Distinguishing self as different from other PLWH who are blameworthy.
Intersectional Invisibility	PLWH Prototype	White, gay, male prototype	Descriptions of the typical PLWH as gay male, usually White.
		Dirty stereotype	Descriptions of the typical

			PLWH as “dirty.”
	Deviation	I'm not like that Expectation	Descriptions of how participants' identities deviated from the typical PLWH.
			Descriptions of how others have not expected participants to be HIV because of their identities.
	Invisibility	Dismissed and forgotten	Reports of feeling as if their needs are dismissed or not considered because they do not fit PLWH prototype.
		Alone	Feeling alone as a PLWH because identities deviate from prototypical PLWH.
		Underestimation of risk	Reports of having underestimated HIV risk because identities deviate from PLWH prototype.