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"When You Tell Them, Your Secret is Out There": Experiences of Sexuality and Intimacy Among HIV Positive Black Women

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“When You Tell Them, Your Secret is Out There”: Experiences
of Sexuality and Intimacy among HIV Positive Black Women

by

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A thesis submitted in partial fulfillment
of the requirements of the degree of
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Abstract

HIV/AIDS infections disproportionately impact African Americans within the United States. In 2010, black Americans made up 12 percent of the United States population, yet accounted for 44 percent of new HIV/AIDS infections (Kaiser Family Foundation 2013). The majority of black women (85 percent) are infected with the virus through heterosexual contact, meaning it is critical examine their sexual lives in order to gain insight into this infection within this population (CDC 2011b). Through semi-structured interviews at a Tampa, Florida AIDS service organization, this study presents the experiences of sexuality and intimacy among HIV positive black women. Results demonstrate that HIV impacts much more than sexuality in the lives of these women, and that their sexual and romantic satisfaction, disclosure patterns and mechanisms for decreasing further transmission are influenced by emotional connections, feelings of closeness, love, and intimacy, and are often motivated by non-traditional messages about health.

Chapter 1: Introduction

INTRODUCTION

In the United States, African Americans carry the burden of HIV/AIDS infections. In 2010, they made up only 12 percent of the nation's population, yet they accounted for 44 percent of all new HIV/AIDS cases (Kaiser Family Foundation 2013). In addition to having the highest prevalence, they also have the highest rates of new infection (CDC 2011a). Black men who have sex with men (MSM) account for 70 percent of new infections among African Americans; amongst black women, who make up the other 30 percent of these new cases each year, 85 percent contract the infection through heterosexual contact, meaning that men play a critical role in the continued transmission of the virus (CDC 2011b). In 2011, HIV was represented as a top ten cause of death among black women ages 15 to 64, yet was not represented in the top ten causes for white women of any age (Heron 2012). Table 1 provides data on the rank of HIV as a top ten cause of death among women of various ethnicities in the United States.

TABLE 1. Rank of HIV as a top ten cause of death among women in the U.S., by ethnicity.

Age in Years	White	Black	Hispanic	Asian
20-24	—	7	—	—
25-34	—	5	—	—
35-44	—	3	10	9
45-54	—	5	10	—

Data derived from Heron 2012.

In the U.S., a white woman has a 1 in 526 lifetime chance of contracting the virus, while a black woman faces a 1 in 32 chance (CDC 2011b). These statistics highlight the need to conduct research to not only discover the reasons for this health disparity, but also to tailor primary prevention efforts toward black women who are disproportionately at risk, as well as improving the socially and historically rooted conditions that create this stark disparity.

In 2010, Florida had the third highest rate of AIDS cases in the United States, with 36.4 per 100,000 people infected, compared to 21.9 per 100,000 infected throughout the entire country (Lieb 2011). Blacks (i.e., African Americans, Caribbeans, and other individuals of African descent) have the highest rates in Florida as compared to other ethnic groups, with an incidence of 123.7 cases per 100,000 among blacks, 18.8 per 100,000 among whites, and 32 per 100,000 among Hispanics (Lieb 2011). Of those African Americans infected in Florida, 41 percent are women (Lieb 2011).

HIV AND SEXUALITY

While much public health and social science research has contributed to uncovering the causes of the HIV/AIDS health disparity and preventing additional infections, admittedly, within both public health and anthropology, there has been “widespread neglect and even marginalization of sex research over much of the twentieth century,” (Parker 2001:164) which only contributes to stigma and discrimination and slows down progress in the fight against HIV/AIDS. Sexuality is often left out of the HIV/AIDS equation, failing to consider pleasure and its pursuit as worthy of attention (Higgins and Hirsh 2008). This thesis seeks to challenge this by specifically studying the sexual lives of HIV positive black women, who, along with their male counterparts, are

uniquely and unequally infected with HIV/AIDS. The understanding of sexual decision-making and embodied encounters of these women from an anthropological perspective can inform public health efforts that seek to decrease HIV transmission, and improve the quality of life of those living with this chronic condition.

INTRODUCTION TO THE EPIDEMIC

The factors that contribute to the HIV/AIDS health disparity are complex, nebulous, and cannot be reduced to a single cause. They range from larger, macro level forces rooted in historical, political, social, and economic circumstances to more individually-based inter and intrapersonal influences. For example, on a broad, societal scale, black Americans live disproportionately in poverty (DeNavas-Walt et al. 2012) due to longer bouts of unemployment and lower pay rates than other groups (U.S. Bureau of Labor Statistics 2012; Williams and Prather 2003), and are less likely to have health insurance (Smedley et al. 2003; Williams and Prather 2003), frequently due to working jobs that do not offer employee insurance coverage (Williams and Prather 2003). Preventive health care is difficult to obtain, and those able to find care face a finite number of providers, extended waiting periods, and a lesser overall quality of care (Williams and Prather 2003). Poverty is often concentrated in inner cities due to racialized housing segregation, meaning lower quality education systems, fewer employment opportunities, and denser sexual networks, which is especially problematic in terms of sexually transmitted infections (STIs), including HIV (Williams and Prather 2003). African Americans, as a group, have the highest incidence of STI infections, including Chlamydia, gonorrhea and syphilis in the United States (CDC 2012), which when left untreated, makes them more susceptible to acquiring an HIV infection

(Fleming and Wasserheit 1999). These structural factors are intensified by interpersonal and intrapersonal level factors that are also said to contribute to this HIV/AIDS disparity.

On an interpersonal level, black women who are economically disadvantaged are likely to rely on men to meet the needs of themselves and their children, and may forgo condom use to please or placate their providing partner (Friedman et al. 2009; Wingood and DiClemente 2000). In circumstances of drug addiction, women may also engage in the exchange of sex in exchange for money or drugs on the streets (Romero-Daza et al. 2003). Great numbers of black men are removed from society due to high rates of incarceration and homicide, and some men may take advantage of women's willingness to sacrifice due to the demand created by their "relative scarcity" (Adimora et al. 2002:710). Within these relationships, assumptions of monogamy and a premium placed on trust means condoms may not be seen as necessary (Sobo 1995).

Finally, gender role expectations influence both inter and intrapersonal relationships and contribute to HIV/AIDS transmission. Due to the difficulty to advance sociopolitically, black men may overcompensate sexually by engaging in frequent and concurrent sexual relationships (Whitehead 1997), while women in relationships may be too trusting of their partner's assumed fidelity in order to maintain social appearances of having the "conjugal ideal," a faithful monogamous heterosexual relationship (Sobo 1998:79). As will be discussed later, anthropology tends to focus on the former (macro-level causes) and public health on the latter (inter and intrapersonal level factors). Both of these areas of focus are essential in order to understand this healthy disparity, yet carry their own assumptions.

This thesis will focus on the experiences of HIV positive women, yet to understand their infection risk it is necessary to include a discussion of black males. As one half of the HIV transmission equation, black men are said to exaggerate their masculinity through overemphasizing sexual prowess to make up for their lack of financial and status advancement (Bowleg et al. 2011; Whitehead 1997). This drives their involvement in concurrent sexual relationships, which are said to be more frequently among black Americans, creating pockets of infections within concentrated sexual networks (Adimora and Schoenbach 2002; Aral 2008; Morris 2009). Other men live “on the down low,” meaning they portray a heterosexual lifestyle within relationships with women while engaging in sex with other men, often bringing HIV into what the female partner believes to be a monogamous, and thus safe, relationship (Dodge et al. 2008; Han et al. 2010; Martinez and Hosek 2005). On a larger scale, elevated incarceration rates due to harsher punishment for crimes spurring from the “War on Drugs” increase black men’s risk of exposure to the virus behind bars (Blankenship et al. 2005; Lane et al. 2004; Millett et al. 2006). This is mainly due to the fact that prisoners have higher prevalence of HIV than the general population, and few prisons provide condoms to inmates who may engage in sex with other men (Braithwaite and Arriola 2003). Injection drug use in prison creates heightened risk as well, as few institutions offer clean syringes to inmates (Blankenship et al. 2005; Braithwaite and Arriola 2003). An astounding one-quarter of black men will be incarcerated in their lifetime (Blankenship et al. 2005), which creates unbalanced sex ratios in American society and increases the probability that women will compromise their health (e.g., not insisting upon condom use) to keep a partner around (Lane et al. 2004).

It has been suggested that black women may often place their health at risk in order to advance financially, by trading or offering sex as an exchange for money (Wingood and DiClemente 2000). That is, in an effort to keep a partner that offers them financial stability, they may engage in sexual behaviors that increase their risk for HIV (Aral et al. 2006; Forna et al. 2006; Wingood and DiClemente 2000). On the other hand, Sobo (1995) posits that, rather than seeking financial security, inner city women deny their risk based upon a desire to increase self-esteem and maintain social appearances that dictate the need to be part of a trusting, loving relationship (Sobo 1995; Sobo 1998). As mentioned previously, black men struggle to maintain employment and adequate wages, and are frequently exposed to increased violence and jail time (Sobo 1998). Therefore, Sobo believes, it is unrealistic to expect they have the financial ability to support women as some literature suggests (Sobo 1995; Sobo 1998). Explaining black women's unsafe sex through a lens of financial dependence allows scholars to rationalize such a choice, whereby "profit-seeking makes sense according to capitalist logic" (Sobo 1998:78). Instead, for many women, self-esteem is rooted in their ability to attract and keep a man, and their social status is boosted by choosing a faithful, disease-free partner with whom the use of condoms is unnecessary (Sobo 1998). The use of condoms would signify distrust, a lack of intimacy, and ultimately a "failure" of a relationship (Sobo 1998:79).

Most broadly, poverty is responsible for a number of negative health outcomes among black Americans due to lack of access to health care (Farmer 1999; Williams and Prather 2003), unsafe and inconsistent housing (Aidala and Sumartojo 2007), and psychosocial stress (Dressler et al. 2005; Mays et al. 2007). Due to the various phenomena thought responsible for the heightened prevalence of HIV among black

Americans, men or women cannot be studied independently, but together to understand the nature of and power within their interactions in order to gain an entire view of how HIV saturates a community. Thus, it is essential to factor in the role of men when examining the lives of women with HIV.

LIVING WITH HIV/AIDS

Persons infected with HIV face numerous challenges in addition to their health status including stigma (Barroso and Powell-Cope 2000; Lawless et al. 1996; Sandelowski et al. 2009), poverty (Aranda-Naranjo 2004; Farmer 1999), and overburdened federal programs which provide assistance including housing (National AIDS Housing Coalition n.d.) and medication to those infected (Kaiser Family Foundation 2012). In addition, they must navigate their romantic and sexual lives while dealing with the reality of being infected with an incurable sexually transmitted virus. Disclosing one's HIV status and engaging in sexual activity while infected can bring a great deal of fear and uncertainty (Gurevich et al. 2007; Kalichman and Nachimson 1999; Marks et al. 1999). Sex suddenly becomes more than an act; it can infect another person with HIV.

It is well evidenced that even though they and their partners may be aware of the dangers of unprotected sex, many HIV positive women continue to engage in risky sexual behaviors (Bova and Durante 2003; Kalichman and Nachimson 1999; Sowell et al. 2003). This research looks to gain insight into the factors that impact the decision of HIV positive women to engage in unprotected sex. Using a qualitative approach, the project seeks to examine a variety of issues such as who is involved, what is at stake, what factors are considered when having sex as an HIV positive black woman—with the

ultimate goal of providing health care workers and public health practitioners ethnographic evidence to consider when creating secondary and tertiary prevention interventions that respond to the reality of the clients' lives.

ANTHROPOLOGY AND PUBLIC HEALTH

Since HIV was first reported in 1981, prevention efforts have been largely centered on changing individual behaviors—e.g., increasing the use of condoms, choosing monogamy, avoiding needle sharing (Adimora and Schoenbach 2002; Aggleton 2004; Marks et al. 1999; Parker 2001). Specifically, public health programs and interventions continue to place the burden of responsibility on the individual to protect themselves from HIV infection (Aggleton 2004; Parker 2001; Singer 1998). Along with this comes the assumption that humans, when equipped with enough knowledge about a topic, will naturally make the rational choice, which is to protect themselves from HIV by way of condoms or other barrier method, monogamy, or never sharing needles (Adimora and Schoenbach 2002; Marks et al. 1999; Singer 1998). Rooted in economic theory, it is assumed that rational choices (such as protecting oneself from HIV infection or protecting one's partner via status disclosure) are made systematically by those who calculate options and make the best decision based upon empirical evidence and reason (Simon 1955). This approach, which makes the choices of unsafe sex or needle sharing seem irrational, simplifies men and women to the status of "*homo economicus*," who chooses the option that has more pros than cons on their list of potential outcomes (Van Campenhoudt 1999:186). This individualistic method, said to be "too simplistic," views risk taking through dichotomous lens of either/or choices (Van Campenhoudt 1999:186)

and disregards the impact of interpersonal, social, and structural factors in limiting an individual's ability to protect his/her sexual partners from infection with HIV.

Epidemiological studies generally focus on rapid data collection assessing factors such as the number of sexual partners, frequency of different sexual acts (e.g., vaginal, sexual, and oral sex), rates of condom use, disclosure of serostatus to partners, and compliance with medications (Rice et al. 2006:164). While important to understand risk from a statistical point of view, such approaches tend to “decontextualize” this information from the “social processes that are both historically rooted and linked to persons,” most of which are “not visible” to the researcher (Castro and Farmer 2005:53). It seems behavior alone becomes a method to categorize people—who is more or less likely to contract HIV-- without considering factors which are beyond their control but certainly play a role in their infection likelihood. Further, most public health and epidemiological reports are quick to identify groups as being “at-risk,” in turn grouping individuals in order to implement preventive practices (Nguyen and Peschard 2003:457). Anthropologists are hesitant to subscribe to this discourse of “at-risk” groups, as it “subjects individuals and social groups to forms of “discrimination” and further reinforces “stereotypes” and “stigma” (Nguyen and Peschard 2003:458). Placing people at risk and the incurring stigma often convey messages of morality or worthiness, which are a serious threat to the commitment needed to successfully defeat HIV/AIDS.

Singer (1994) refers to AIDS as an “*opportunistic disease*” which arises from poverty (937, original emphasis). He argues that the examination of HIV cannot simply follow the “short-sighted” model that over-emphasizes “‘risk groups’ and ‘risk behaviors’”. Rather, it should not be divorced from the “unhealthy” social, environmental

and political situations of the poor (Singer 1994:937). Additionally, the creation of risk groups on the basis of behavior alone often incorrectly assumes “common sociocultural identities and unified attitudes and values,” and denies existing idiosyncrasies (Singer 1998:12). The actions of individuals must be considered in the broader spectrum of the social body and the body politic, otherwise risk will continue to demarcate African Americans and other groups. Anthropologists are able to provide an essential “translation” of public health policies into socially and culturally understood and acceptable models, yet they fall short when it comes to developing programs of their own, which is a strength of public health (Hahn and Inhorn 2008:6).

Within medical anthropology, theories such as structural violence and the political economy of health paint pictures with broader strokes, seeking to take the onus of responsibility off the individual and instead focus on the situations that constrain their agency as the source of increased HIV infection (Janes and Corbett 2010; Singer 1994). Singer (1998) provides the example of needle sharing among injection drug users (IDUs) to illuminate political economic effects on health. Though IDUs are aware of the dangers of sharing their needles, including the risk for AIDS, laws that make carrying needles a crime and the requirement of a prescription in order to obtain clean needles create a “structurally imposed needle scarcity” and lead IDUs to place themselves at risk (Singer 1998:14). Thus, what may look like an irrational “choice” to knowingly expose oneself to HIV or other infections via shared needles is actually a forced decision made according to structural impediments. Accordingly, it is crucial to look beyond individuals and examine how risk is “structure[d]” around them, limits their choices (Singer 1998:15), and perpetuates hegemonic power structures (Singer 1998:22).

It is often a struggle to find a middle ground between the rationale-based public health education efforts that place individuals responsible to make safe and healthy choices and wider anthropological views that place historical, economic, social and political factors as most influential on the health of the poor. For this project, the research questions and understandings of why black Americans are so unequally affected by HIV/AIDS tend to be theoretically rooted in the latter, because elements such as poverty, inaccessible resources, inadequate housing, and underpaid employment often limit the choices people are able to make. Thus, even though one may know what behaviors are best for their health, such as eating fruits and vegetables, or wearing condoms for sexual activities, they may be without a number of necessary conveniences to facilitate these healthy behaviors as a part of their daily lives. For example, women needing to schedule a clinic appointment may struggle to find childcare, or have to work during a clinic's hours of operation. Men with a felony conviction have severe restrictions to government assistance (Blankenship et al. 2005) and be unable to afford to take a day off of work to visit a doctor for a suspected sexually transmitted infection. These examples are illustrations of potential roadblocks people may face to engaging in health behaviors, despite their knowledge of what public health experts say is best for them.

Fortunately, the use of the Social Ecological Model (SEM) provides a structure with which to analyze the competing paradigms of macro versus micro level causes of health. The SEM consists of five levels that all equally influence and interact with a person (or group of persons) to affect their health; these levels are: 1) intrapersonal; 2) interpersonal; 3) organizational; 4) community; and 5) societal (Coreil 2010). This holistic approach allows for the integration of factors ranging from proximal to distal and

for a broader, more inclusive view of a health problem (Coreil 2010). Further, use of the SEM allows health to be influenced at several levels, creating various leverage points for interventions or programs (Rimer and Glanz 2005).

Accordingly, the various levels of influence on health are interconnected, making it essential consider how changes on one level can impact the other levels. The construct of “reciprocal determinism” within the Social Cognitive Theory (SCT) is a useful tool for considering the interrelationship and fluidity between causal factors. Reciprocal determinism suggests an individual, their behavior, and their environment are equally influential upon one another, whereby if one element changes, a shift will necessarily occur in another (Rimer and Glanz 2005). More, SCT relies heavily upon the construct of self-efficacy, or the confidence one has that they are able to perform a certain behavior in a number of different settings (Rimer and Glanz 2005). Self-efficacy and the behaviors it promotes or inhibits are influenced by a number of other related concepts, including behavioral capability (having the knowledge or skill to perform the behavior), outcome expectations (anticipated result of the behavior), modeling (what behaviors are being performed in the environment around the individual), and reinforcements (what actually occurs as a result of this behavior, and its promotion or discouragement of this behavior to be repeated) (Rimer and Glanz 2005).

For example, a woman’s self-efficacy for ensuring condoms are used with her partner is shaped by a number of factors, including what she anticipates her partner’s response will be to her request for condoms (outcome expectations), and how her friends or peers approach this same situation (modeling). Once she has gained enough self-efficacy, her behavior is likely to change (condoms will be used during sexual activities).

Depending on the actual outcome of the situation, she will receive reinforcements or deterrents to performing this behavior again. Accordingly, the environment is affected as well, based upon, for example, whether the sexual partners of this woman may begin to feel using condoms is the norm. The notion of reciprocal determinism, the idea that a person, their actions and their surroundings are constantly influx and influencing one another is useful when considering the multitude of factors considered to play a part in the HIV/AIDS epidemic.

In the end, no matter what causes one to become infected with HIV—structural constraints or individual behaviors—living with HIV is likely a difficult road. The unfortunate victim blaming that can result from holding someone individually accountable for their infection is neither productive nor does it change the infection. Instead, it perpetuates stigma and may incorrectly place individuals into “risk” groups.

STUDY GOALS

The purpose of this research is to understand how HIV positive black women, a group disproportionately affected by the virus, make decisions about their sexual experiences with regard to themselves and in relation to their partners. One of the main foci is to understand how their HIV infection has affected their experiences of sex and intimacy. Whether or not women decide to disclose to their partners, what motivates them to hide or share their status, and how this impacts condom use are important questions addressed in this study as well. Disclosure and condom use have legal, ethical, and health related consequences that are worthy of understanding, especially in the context of life as a black American woman with HIV/AIDS.

A WORD ON LANGUAGE CHOICE

Throughout this thesis, the terms “black,” “black American” and “African American” are used interchangeably. Both “black” and “black Americans” suggest a wider range of ethnic and cultural variation, allowing for individuals who may not identify as African American, or with heritage outside of Africa, such as Afro-Caribbean.

It is also essential to note that the terms “race” and “ethnicity” are used throughout this research as socially constructed concepts and are not intended to suggest any biological or genetic variations that are frequently assumed to be inherent in racial difference (Goodman 2000; Gravlee et al. 2009). When used here, race or ethnicity is most meaningful in terms of self-identification of participants, generally through phenotypic traits such as skin color.

Also, though many of the women whose data are presented here are currently living with an AIDS diagnosis (defined by a CD4 count of less than 200 or by the presence of one or more opportunistic infections [Wiley and Allen 2009]), they are referred to as living with HIV, being HIV positive, or being sero-positive instead of specifying whether they have had an actual AIDS diagnosis. Anecdotally, a staff member at Francis House, the agency where this research was conducted, explained that an official AIDS diagnosis was more important during the early years of the epidemic, as it allowed individuals to qualify for governmental benefits such as disability. Today, he says, an AIDS diagnosis alone is not enough to receive these, and is therefore a less essential categorization.

THESIS OUTLINE

The purpose of this thesis is to present findings from research conducted at Francis House, a local non-profit organization that provides various services to individuals living with HIV/AIDS. Participant observation and semi-structured interviews were used to collect data seeking to understand how the relationships, intimacy, and sexual experiences of HIV positive black women have been affected by their diagnosis.

Chapter 2 is a more in depth look at the background literature including the research that has provided evidence about the factors contributing to the HIV disparities found in the U.S., in particular, structural violence, culturally unique influences, and gender role expectations. The second half of the chapter explores what social science and public health literature says about the lives of women following their diagnosis, taking special consideration of condom use, disclosure patterns, sexual enjoyment and satisfaction, and how each of these factors may vary according to a partner's serostatus.

Chapter 3 describes the setting for this research, Francis House, and the methods used to collect data. Additionally, this chapter includes a discussion on the positionality of the researcher, and of how such position may have helped or hindered acceptance by participants and the collection of information.

Results from the data collection will be presented in Chapter 4, detailing the themes and commonalities as well as the heterogeneity of the women who participated in this research project. Because of the very small sample size (n=9), no broad generalizations can be made. Instead, the chapter focuses on how the stories told by

these women fall into common themes, and explores the diversity of experiences within these themes.

The final section, Chapter 5, will provide interpretation and discussion of the results presented in Chapter 4. In addition, recommendations will be provided based upon the study findings. Finally, limitations of the study will be presented.

Chapter 2: Background

INTRODUCTION

There is no one single reason that can explain why HIV affects the black community in the United States at a disproportionate rate. Structural factors affect all black Americans and limit their access to health promoting resources, increasing their rates of various diseases to levels higher than those found among other ethnic groups. These limitations, when placed in context of women and men's typical gender roles and cultural expectations, contribute to the HIV disparity among black Americans. In order to contextualize this health disparity, it is important to begin by discussing the macro forces that are said to contribute, including historical racism and discrimination, poverty and the consequential lack of access to resources, including housing, employment opportunities, and health care. Next, closely linked, is structural violence, said to work hand in hand with poverty and discrimination, leading to limited choices in terms of health and well-being (Farmer et al. 2006). Next, elevated rates of incarceration, unequal sex ratios, and gender role expectations that create an environment unique to black Americans and are said to add to the complex web of disease contributors will be discussed. Finally, the section that follows will align more closely with the research goals and questions, mainly concerning life after an HIV diagnosis and how relationships and sexuality are affected.

STRUCTURAL FACTORS

Throughout the nation, 15 percent of the U.S. population lives in poverty as defined by the U.S. Census Bureau, yet the black population has a poverty rate of 27.6 percent (DeNavas-Walt et al. 2012). The 2011 United States Census reveals that blacks have the highest poverty rate of any other racial group; Hispanics follow close behind blacks at 25.3 percent, Asians at 12.3 percent and whites at 9.8 percent living below the poverty line (DeNavas-Walt et al. 2012).

Due to these disproportionate poverty rates, black Americans also suffer from limited access to quality health care (Williams and Prather 2003). Nearly 16 percent of all Americans lack health insurance coverage, with black Americans and Hispanics being uninsured at elevated rates; 19.5 percent and 30.1 percent, respectively (DeNavas-Walt et al. 2012). Comparatively, white Americans are uninsured at a rate of 14.9 percent, and Asians at 16.8 percent (DeNavas-Walt et al. 2012). An Institute of Medicine report claims one's health insurance coverage may be more influential on "timeliness and quality of healthcare" than any other factors, including economic status (Smedley et al. 2003:84). In comparison to whites, black Americans are more likely to be covered with Medicaid or other public entity (Smedley et al. 2003). Employment, too, is related to a lack of health insurance among blacks because they more often work jobs that do not offer employee insurance coverage (Smedley et al. 2003)

With respect to employment, black Americans face higher rates of unemployment, earn lower median wage, and face longer bouts of unemployment than whites and Hispanics (U.S. Bureau of Labor Statistics 2012; Williams and Collins 2001). In 2011, blacks had the lowest annual median household income earnings at \$32,229,

followed by Hispanics at \$38, 624, white Americans at \$55, 412 and Asians at \$65,129 (DeNavas-Walt et al. 2012). As of February 2012, black women, in particular, had double the rate of unemployment of white women (12.4 percent versus 6.8 percent, respectively) (U.S. Bureau of Labor Statistics 2012).

Institutional racism, less overt and tending to be woven into power structures and policies, is another consideration when examining the HIV epidemic. Though it is often more difficult to observe than overt racist expressions or behaviors, institutional racism systematically oppresses a group deemed inferior, and among blacks, frequently plays out through unfair mortgage lending, housing segregation, employment opportunities, and within the criminal justice system (Smedley et al. 2003). For example, racially-based housing segregation is a symptom of past discriminatory policies and a residual effect of historically rooted poverty; black Americans tend to live clustered in inner cities which creates limited access to nearby medical care, healthy food options, municipal services, job opportunities and sufficient education, and increases exposure to environmental risks such as homicide and violence (Williams and Collins 2001; Williams and Williams-Morris 2000). Areas of segregated housing have more concentrated poverty, resulting in less funding for local schools (Williams and Williams-Morris 2000). Lesser quality education is said to contribute to higher rates of dropout and lower academic achievement, thus resulting in insufficient training and skills for gainful employment (Williams and Williams-Morris 2000). In addition, segregation increases physical proximity, which heightens HIV exposure because most people tend to choose partners from the same racial/ethnic group, which naturally makes disease transmission more

likely based upon its higher concentration among blacks (Friedman et al., 2009; Lane et al. 2004).

Structural Violence

Much social science literature on HIV discourages the focus on individual behavior as a place of modification in the fight against HIV/AIDS (Adimora and Schoenbach 2002; Dressler et al. 2005; Friedman et al. 2009). Instead, by looking at the larger social, political, economic, and environmental factors, anthropologists can help to make sense of this and other health disparities. Paul Farmer offers the concept of structural violence to explain the often-widespread “oppression on the health of the poor” in place of traditional public health measures that tend to focus on “risky behavior” (Janes and Corbett 2010:407).

Paul Farmer (2004) defines structural violence as “violence exerted systematically—that is, indirectly—by everyone who belongs to a certain social order” (307). Specifically, structural violence occurs within “social structures characterized by poverty and steep grades of social inequality, including racism and gender inequality” (Farmer 2004:307). Within the U.S., structural violence prevents black Americans from “reaching their full potential” and makes them more likely to become infected with HIV because they are limited socially (Farmer et al. 2006:1686). These limitations may come in the form of poor access to resources, concurrent coexisting illnesses, malnutrition, or inadequate housing and job opportunities, all of which are created and compounded by poverty (Farmer et al. 2006:1687).

The tenants of structural violence align closely with the theoretical framework of political economy of health, which recognizes that personal agency is often limited by

historically rooted structural barriers (Singer 1994) and the degree to which both direct and indirect, and macro and micro level influences interact to shape ones life experiences and their health (Carlson 1996). Historically, the work of Virchow and Engels laid the foundation for the understanding of the impact of social conditions on health (Singer 1998). For example, Engels wrote about the effects of “deplorable” working and living conditions on health, finding that those living in lower social classes were the most highly exposed and experienced increased mortality rates because of it (Singer 1998:7). Since then, the political economy of health has been utilized by various social science disciplines to demonstrate that capitalism and free market production lead to class struggles, disadvantaged groups unable to advance socioeconomically, and detrimental effects on their health due to “political powerlessness” (Baer 1982:2) and unequal access to commodities (Singer 1998). The theories of structural violence and political economy of health shift attention away from individual behaviors and decision making towards a wider picture of the circumstances affecting the lives of women in poverty (Farmer 1999; Singer 1998), especially those living with HIV/AIDS.

For black women in particular, structural violence, or the historical, economic, and politically driven processes which “constrain individual agency,” places them at high risk for contracting HIV (Farmer 1999:79). Farmer finds his point well illuminated by Treichler (1988), who states: “In settings of entrenched elitism, they [women infected with AIDS] have been poor. In settings of entrenched racism, they have been women of color. In settings of entrenched sexism, they have been, of course, women” (1999:62). Structural violence places women living in poverty “at risk” long before their sexual encounters with HIV positive men, in fact, they were “born into” risk because they were

born into poverty (Farmer 1999:78). Their agency was robbed from the beginning, leaving them unable to protect themselves from the slew of problems they will face. Unfortunately, for most women of color who are sero-positive, a diagnosis does not change their social standing; poverty, oppression, unemployment and other challenges continue to exist in addition to their health status.

FACTORS UNIQUE TO BLACK AMERICANS

In addition to structural factors impacting those plagued by poverty, black Americans face a number of circumstances that influence HIV infection rates which are specific to their ethnic group. Just as the spread of the virus is mediated by social conditions, the factors to be discussed are socially rooted as well, and include unbalanced rates of incarceration, unequal sex ratios, stigma, and community and church reluctance to address the epidemic.

Incarceration

High rates of black male incarceration is said to increase HIV transmission among African Americans because it removes men from society, creating unequal sex ratios, and because their chance of being exposed to the virus is much greater while in this setting. Like in the case with HIV, black Americans are disproportionately represented in the criminal justice system. In 2003, for every 100,000 residents there were 465 white males incarcerated and 3,405 black males incarcerated; over his lifetime, a white man has a 1 in 23 chance of going to prison, while a black male has a 1 in 4 chance (Blankenship et al. 2005:142). These wide discrepancies are said to be due to the “War on Drugs” beginning in the early 1980s (Bluthenthal et al. 1999:26) which made for “mandatory minimum sentences, penalty enhancements for the sale and use of drugs in certain drug free zones,

disparities in the penalties associated with possession of crack and powder cocaine, and restrictions on syringe availability” (Blankenship et al. 2005:142). These new laws were intended to reduce drug use through fear of potential consequences (Bluthenthal et al. 1999:26). In turn, there was a 1000% increase in the number of inmates convicted of drug offenses between 1980 and 1995 (Blankenship et al. 2005).

These statistics can be misleading though, as the heightened rates of black men in prison do not mean they are committing more crimes. White youth use drugs earlier than African American youth and have higher rates of lifetime use of illicit drugs (not including marijuana), making this incarceration imbalance difficult to understand (Blankenship et al. 2005:141). To further bolster this argument, Alexander (2010) states that white youth present in emergency rooms because of drug related incidents three times as often as black youth, yet blacks represent “80 to 90 percent” of all drug offenders in prison. (76). Until the law was ended in 2007 (Adimora et al. 2009), being arrested for intent to distribute crack cocaine, a drug said to be used more frequently by African Americans, received the same sentence as someone with the intent to sell “one hundred times as much powder cocaine,” which is more likely to be used by whites (Nunn 2002:396).

While the war on drugs has been described as having been “declared against the black poor” (Kelley 1997:100) or even a “War on Blacks” (Nunn 2002:382), Alexander (2010) has renamed the superfluous incarceration of blacks a “new Jim Crow system,” (77) claiming a new “caste” of “second-class” citizens has been created amongst black men who are denied rights for a lifetime based upon their felony convictions, including exclusion from suffrage, government assistance, jury duty, and educational benefits (75).

Nunn (2002) argues that Reagan's War on Drugs specifically targeted communities of color who are viewed as "sources of vice and crime," (390) and made their disproportionate rates of incarceration easier to swallow by white Americans, despite the numbers of arrests and imprisonment among blacks exceeding that of "any legitimate law enforcement interest" (392). Prison populations have increased by more than three times since the beginning of the War on Drugs (Nunn 2002).

Incarceration is problematic in terms of HIV because it creates an environment that facilitates unprotected sexual contact and needle sharing, two highly successful methods of transmission of the disease. Despite sexual activity being "illegal" in all U.S. prisons, it continues to occur and place incarcerated individuals at an increased risk of contracting HIV (Okie 2007:105). With the prison population having an HIV infection rate around 1.8 percent, four times greater than the general population, there is cause for concern because the vast majority of prisons and jails do not provide condoms to their inmates (Blankenship et al. 2005; Okie 2007). In larger jurisdictions, HIV/AIDS prevalence in prisons shoots to rates of 3.9 percent (Florida) and seven percent (New York) (Okie 2007). Okie (2007) reports that only two states, Vermont and Mississippi, and five county jail systems (Philadelphia, New York, San Francisco, Washington, D.C., and Los Angeles) provide condoms on a "limited basis" to inmates (106). Further, no prison or jail in the U.S. is known to offer a needle exchange program despite the occurrence of injection drug use and tattooing (Okie 2007). Higher prevalence of HIV/AIDS in the corrections systems and grossly inadequate access to protective measures for inmates means transmission risk is greatly heightened (Blankenship et al.

2005; Okie 2007), especially for African Americans who are overrepresented behind prison walls (Nunn 2002).

Additionally, gender segregation within prisons increases male-to-male sexual contact (Blankenship et al. 2005). This is problematic because anal receptive sex is the most common mode of HIV infection among men, as well as the easiest way to transmit the virus (Whelehan 2009:117). Inside of prison walls, HIV risk is increased within the black population based upon the high proportion of incarcerated individuals; this in turn increases black men's likelihood of exposure, whether they are infected before or during their sentences (Blankenship et al. 2005:143).

While men are incarcerated, social networks are "disrupted" due to women who find new partners or get divorced while their partner is behind bars, broadening sexual networks (Blankenship et al. 2005:144). This is concerning because it is also possible, that once released, men infected while in prison are bringing their infection back into their homes and communities. These infections would be adding to an already existing high prevalence of HIV, increasing the concentration within segregated neighborhoods and small sexual networks.

Black men often face time behind bars due to drug charges, leading scholars to examine the use of illegal drugs within this population. The most recent Substance Abuse and Mental Health Services Administration's (SAMHSA) *Results from the 2011 National Survey on Drug Use and Health* states that Black and African Americans report high rates of illicit drug use in the month prior to the survey, at a rate of 10.0 percent, following behind American Indians (13.4 percent), Alaska Natives, and persons of two or more races, both at 13.5 percent (SAMHSA 2012). Ethnicities that reported the lowest

rates of drug use in the previous month rates include Asians at 3.8 percent, whites 8.7 percent, and Hispanics at 8.4 percent (SAMHSA 2012). Literature such as this, suggesting African Americans are using drugs more frequently than whites, Hispanics and Asians, may lead to victim blaming, and has even been challenged by social science researchers (Lillie-Blanton et al. 2002). The same SAMHSA report from 1988 claimed African Americans had higher lifetime use of crack cocaine (Lillie-Blanton et al. 2002). Lillie-Blanton and colleagues (2002) caution against accepting this data at face value, and feel that one's community, including availability of crack cocaine, rates of unemployment and early death, involvement with the criminal justice system, among others, may be more determinate of drug use patterns than race itself. By reanalyzing the data and re-stratifying the respondents into neighborhood strata of "shared characteristics," the odds of African American crack cocaine use was no higher than any other ethnicity (Lillie-Blanton et al. 2002:500). Thus, in terms of incarceration and injection drug use and their relation to HIV transmission, it is important to adopt a critical approach of secondary data. These findings support claims that increased rates of incarceration of African Americans may be more racially motivated than due to actual illicit drug use.

Just as in the use of crack cocaine, the work of Lillie-Blanton and colleagues (2002) provides a useful paradigm for viewing the HIV/AIDS disparity as well. Though black Americans are affected with HIV at disproportionate rates, HIV is said to be a "disease of poverty" (Singer 1994:937). Therefore, those living in poverty, regardless of skin color, are more likely to become infected with this disease due to their exposure to

common social, economic and political conditions rooted in their social position, not just their “race” or “ethnicity.”

Sex Ratio Imbalance

Incarceration and elevated rates of homicide remove men from society (Adimora et al. 2009), and are considered responsible for disrupting the male-to-female sex ratio among black Americans. For every five African American women, there is one black man between the ages of 20 and 59, in contrast to white men and women who are of “nearly equal” proportion (Lane et al. 2004:413). Newsome and Airhihenbuwa (2012) report for every 100 females, there are 90.1 black males, 105.1 Hispanic males, 98.7 Native American males, 96.3 white males, and 92.8 Asian males. Moreover, there are naturally more women than men in society; in 2002, there were 13.5 million black women over 18 and 10.8 million black men, leaving 2.7 million females without a male mate even before factoring in incarceration or other mechanisms which remove black men from society (Boykin 2005). It is suggested that based upon this lack of available partners, women may make “sacrifices” in order to keep their partner around (including, but not limited to, having sex without a condom) (Lane et al. 2004:423).

Stigma and the Black Community’s Reaction

Stigma, originally defined by Erving Goffman (1963), is the discriminatory attitudes or behaviors created when there is a perceived difference within a group or an individual in a group, and therefore removes this person or group of persons from what is the perceived norm (Castro and Farmer 2005:54). Further, stigma is often associated with some sort of perceived “moral failure,” (Lichtenstein 2003:2437) which can lead to social exclusion where people “find themselves being blamed” (Nguyen and Peschard

2003:458). Due to the morally fraught nature of HIV transmission—frequently sexual behavior or drug use—HIV remains highly stigmatized (Sandelowski 2009), perhaps more so in the black community than among whites, as HIV was originally seen as a disease of gay white men (Whitehead 1997).

Historical circumstances and religious conservatism contribute to modern-day stigmatization of homosexual behavior and its relation to HIV within the black community as well. Some individuals and organizations alike (e.g., the black Church) have been hesitant to admit susceptibility to AIDS and are unwilling to associate with the “sexual depravity, deviance, and foolish risk-taking” said to cause HIV/AIDS, which could consequently “signal personal inadequacy” (Sobo 1995:38). Quimby (cited in Sobo 1995:38) states that admission that HIV/AIDS is a problem would serve as a marker of “cultural disenfranchisement”. Historical mistrust of medical systems linked to the Tuskegee trials and suggestions that HIV was manufactured by the United States government to eliminate black Americans have left a lasting mark on the views of HIV/AIDS among black Americans (Jones 2011; Sobo 1995).

The influence of the black Church in the lives of African Americans is significant, as 80 percent of blacks claim they follow some “faith tradition,” and 97 percent claim some “religious affiliation” (Ward 2005:494). Ward (2005) provides three explanations for the perpetuation of homophobic attitudes and (in)actions within black churches including 1) biblical teachings, 2) a history of exploitation of black bodies, and 3) race survival motivations. A literal translation of biblical condemnation of homosexuality is common (Ward 2005). The churches’ desire to avoid the topic of sexuality altogether is named as a reason for lack of participation in HIV/AIDS prevention (Ward 2005).

Next, homosexuality is said to be a threat to masculinity, even more so among black men who are pushed towards “hypermasculinity” that plays out in sexual prowess (Ward 2005:497) or a “hustling” lifestyle (Whitehead 1997:434). Stereotypes of black hypersexuality and historical fascination with black sexuality among whites are also said to contribute to excessive homophobia (Ward 2005). Finally, efforts to disprove stereotypes and fight against “white domination” also serve as mechanisms that perpetuate homophobia (Ward 2005:496).

Male Gender Role Expectations

In light of the structural and cultural factors previously discussed as contributing to the HIV disparity among black Americans, it is essential to consider interpersonal relationships between men and women, as they serve as the actual transmission point for the virus.

The structural factors previously discussed, including historical and institutional racism, cause black men to struggle with advancing socially and economically, therefore pushing them to overcompensate sexually (Whitehead 1997). This, too, is one of various reasons said to contribute to concurrent sexual relationships among black Americans, a pattern that plays a role in more rapid spread of HIV infection (Admiora and Schoenbach 2002; Adimora et al. 2009; Bowleg et al. 2011).

Whitehead (1997) uses the concept of “male gender self” to explain what men feel they need to be in order to be worthwhile in the black community (419). The gender self consists of “economic, sociopolitical, and sexual,” powers, all of which require fulfillment in order for a man to meet masculine ideals (Whitehead 1997:419). Yet, barriers and limited opportunities have restricted black men from achieving a balance of

all of these three elements (Whitehead 1997). “Lower socioeconomic status, unemployment, and underemployment” are the root of this fragmentation; men who are unable to gain economic capacity are unlikely to gain sociopolitical power because the two are so closely linked (Whitehead 1997:419). Thus, black men may see themselves as “fragmented,” and atone within the sexual realm to feel some semblance of control in their lives (Whitehead 1997:419). Their power, instead, comes from “social subordination” of women and through controlling women’s sexuality and reproduction (Whitehead 1997:420). The need for overcompensation is echoed by Majors and Billson (1993) who use the term “cool pose” to describe male efforts to fight against being “psychologically castrated” by “racism and discrimination” (1). By “emphasizing strength, toughness, pride, control, poise and emotionlessness,” black men are resisting current and past white dominance (Ward 2005:497).

Bowleg and colleagues (2011), too, found that black men feel their masculinity lies in their sexual prowess, and that having sex with many women was “intrinsic” to their identity (55). In their research in Philadelphia, Bowleg and colleagues (2011) found that focus group participants felt unequal sex ratios in society due to death and exaggerated incarceration for black Americans placed them at an advantage when seeking women (Bowleg et al. 2011). In fact, “real” men were lauded for their ability to advance sexually with multiple women, often concurrently (Bowleg et al. 2011:550). At times, these men felt the sexual prowess of women was so “overpowering” that they felt “robbed of their agency to use condoms,” pushing responsibility onto women to ensure safer sex (Bowleg et al. 2011:552). Being overwhelmed by the sexual advances of women was used as a reason they may place themselves at risk for HIV or other

infections, simultaneously blaming women for condomless sex and insisting it is their responsibility to ensure their use (Bowleg et al. 2011).

Male gender expectations, when in conjunction with stigma against homosexual behaviors, have contributed to a phenomenon called “men on the down low” within the black community (Martinez and Hosek 2005:1103). Black men on the down low identify as heterosexual and are often maintaining active relationships with women, yet engage in covert sexual activities with other men (although such secretive behaviors are certainly not limited to black men). The percentage of black men on the down low is estimated around two to three percent of the population (Malebranche et al. 2010), but is thought to be higher among blacks and Hispanics than among white men (Lapinski et al. 2010). Scholars suggest down low behavior may be a source of HIV transmission to women who are in heterosexual relationships (Bond et al. 2005; Lapinski et al. 2010; Martinez and Hosek et al. 2005; Millett et al. 2005), creating what is known as the “bisexual bridge” (Malebranche et al. 2010). The stigmatized nature of homosexuality means that men having sex with both men and women (MSMW) are less likely to disclose their behaviors to female partners, who believe their relationship is monogamous, and forgo the use of condoms (Dodge et al. 2008; Lapinski et al. 2010). If condoms are not used consistently or at all within their relationship, it may signal infidelity if the male abruptly suggests their use when the couple does not generally use them for sexual activities (Small et al. 2009:255). Finally, men on the down low is only one possible mode of bringing STIs or HIV into a relationship; infidelity is possible from one or both partners, with any gender.

From a public health standpoint, targeting men on the down low for HIV prevention remains challenging (Lapinski et al. 2010), as it can be difficult to

differentiate between bisexual behavior and bisexual identity (Malebranche et al. 2010). Malebranche's (2010) study of black men in Atlanta who reported having sex with both a man and a woman in the previous six months (n=38) found that the "majority" of participants differentiated between more or less "gay" sexual behaviors with men, stating that they most frequently engaged in receptive oral sex or insertive anal sex, considered a "less gay" behaviors (161), indicating a rift between behavior and identification as a homosexual or bisexual individual. Those who were willing to be the anal receptive partner, placing them in a submissive, or "more gay" role, claimed it was due to their being in a more serious, "committed" relationship, under the influence of drugs or alcohol, or was done in exchange for money (Malebranche et al. 2010:161).

As will be discussed in the upcoming section on female gender role expectations, the fact that men may be on the down low is a genuine threat to female health when a heterosexual relationship is considered monogamous, and condoms are not deemed necessary for protection from outside infections.

Female Gender Role Expectations

In terms of women, Wingood and DiClemente (2000) use Connell's (1987) Theory of Gender and Power to explain why women, especially women of ethnic minorities, suffer worsened health due to gender based power imbalances. This theory consists of three tenants, none of which can be completely unraveled from the others. These are: the sexual division of labor, the sexual division of power, and the structure of cathexis, or of affective attachments and social norms (Wingood and DiClemente 2000). These three areas where gender power imbalances exist exert themselves at the societal and institutional levels, which include work/career, schools, families, the media, medical

systems, relationships and religious establishments, as well as play out within interpersonal relationships; the wide breadth of these tenants mean they are virtually inescapable by financially limited women of color (Wingood and DiClemente 2000). Women are disadvantaged because of the exposures that are created by holding a place of less power, because of their being a woman in an androcentric society (Wingood and DiClemente 2000). The theory of gender and power allows for more exploration of how gender roles and social norms are created than does structural violence, yet both are in agreement that poverty exacerbates inequalities, especially among women.

In their discussion of the sexual division of labor, Wingood and DiClemente blame traditional “women’s work”—work based in the home (i.e., caring for children, elderly and those who are ill) as an element contributing to the limited power held by women. Often unpaid and undervalued, women find themselves reliant upon men for their financial needs (Wingood and DiClemente 2000). Unemployment remains high for black women, who face double the rate of unemployment as white women (12.4 percent versus 6.8 percent, respectively) (U.S. Bureau of Labor Statistics 2012). In cases where women are in the traditional work force, opportunities are limited to marginal jobs and part time work (Wingood and DiClemente 2000). Some women even find themselves “sliding into survival sex,” which they may feel is their only option to obtain money in situations of drug addiction, families to feed, and limited education and skills (Mallory and Stern 2000:587). Wingood and DiClemente classify sex work as a “high demand and low control” occupation, and one that contributes to power differentials and exploitation, two damaging aspects related to the sexual division of power and the structure of social norms and affective attachment. Within relationships, the sexual division of power

dictates that women wield less decision-making power, which is especially problematic considering their financial disadvantages (Coreil 2010). This lack of power translates to limited ability to demand condom use (Kalichman et al. 1999; Lane et al. 2004; Wingood and DiClemente 2000). In turn, limited condom use, in relation to power inequalities, social norms, and gender expectations of women, increases women's vulnerability to HIV infection (Coreil 2010).

Sobo's (1995) work with low-income, minority women in Cleveland elucidates women's perspectives and perceived roles, even contradicting Wingood and DiClemente's suggestion of financial dependence on men. Sobo suggests an explanation of HIV risk taking that relies solely on women's disadvantaged financial position and the opportunities men may present to them actually "perpetuates racism and classism: it would never be used to explain sexual risk taking among white women belonging to the middle and upper classes." (Sobo 1995:75). Instead, the women involved in Sobo's Cleveland based research claim men are limited, at best, in their ability to provide financially due to their own struggles with unemployment and imprisonment, meaning there must be more than financial incentives to keep women around (Sobo 1995). Instead, Sobo suggests, these inner city women engage in unsafe sex in hopes of maintaining cultural ideals of gender norms (1995). In order to upkeep social images to women around them and to build their statuses and self-esteem, they live according to the "Wisdom Narrative" and the "Monogamy Narrative," which drive their HIV risk denial (Sobo 1995:113). According to the wisdom narrative, a woman knows how to identify a "clean (disease-free)" and "conscious (honorable)" man, and accordingly does not need to use condoms (Sobo 1995:114). One's ability to find a "good" man is considered even

more impressive when the shortage of men is taken into consideration (Sobo 1995:108). To use condoms once in a monogamous relationship would go against the monogamy narrative, which allows women to claim their man is different from the men of other women, and would never be unfaithful (Sobo 1995:116); to use condoms would signal a rift between them, suggesting they are not fully committed and may have outside sexual partners (Sobo 1998). Condoms, many believe, are only necessary within a marriage for contraceptive purposes, because marriage eliminates HIV risk (Sobo 1997). Having sex without a barrier is a luxury available only to women with “faithful partners,” and serves to mark their place in a social hierarchy where only the most ideal couples exist (Sobo 1995:107).

Women living according to the “monogamy narrative” asserts are denying their HIV risk for the sake of love, trust, and social expectations, not for financial security or advancement (Sobo 1995). It is within heterosexual relationships that women obtain what they cannot on their own: “status and emotional fulfillment” (Sobo 1995:102). Though Sobo believes women are willing to go without condoms and place themselves at risk due to a desire to elevate their social standing among peers and to bolster their own self-esteem, she does not deny the influence of “political economic circumstances associated with capitalism” that create gender role expectations and culturally acceptable relationship practices (Sobo 1995:75).

Rhodes and Cusick (2000) build upon Sobo’s (1995) argument, suggesting that self-identity, previously rooted in family or religion, is currently defined more frequently through “love or sexual partnerships,” which help to “secure self-identities in a world characterized by uncertainty” (4). Furthermore, being part of an intimate relationship

may mitigate the uncertainty commonly due to the “impersonal nature of our modern world,” making “love and intimacy” into “strategies of relationship risk management” (Rhodes and Cusick 2000:4). Accordingly, Sobo’s (1995) monogamy narrative and wisdom narratives may serve as mechanisms of relationship risk management in a world of uncertainty created by political economic disruption.

The idea of the wisdom narratives and monogamy narratives are especially threatening to women’s health considering the possibility of men being on the down low. As male-to-male sexual contact is highly effective mode of HIV transmission (Whelehan 2009:117), women are likely to be introduced to the virus if their partners are participating in such behaviors. When Sobo asked participants about the possibility of becoming infected with HIV by a cheating partner, they felt it was just a chance they had to take; condoms were simply not necessary within their “perfect intact unions” (Sobo 1998:79).

Although black women are not a homogeneous group, the literature states they likely place great importance on being in a relationship (Kyomugisha 2006), and may be hesitant to push the issue of condom use in order to not appear pushy or dominant, a trait considered unfeminine (Hearn and Jackson 2002). Unfortunately, the shortage of black men available to women may lead women to compromise their own health even further in order to maintain their current relationships (Lane et al. 2004). Due to the fact that the male condom is the primary mode of prevention for public health efforts, men are given a position of power due to their necessary participation in the use of this contraceptive method (Harvey et al. 2002; Kyomugisha 2006).

LIVING WITH HIV/AIDS

Life After Diagnosis

Unfortunately, once an African American is diagnosed with HIV, the structural, cultural, and gendered factors that create the epidemic are unlikely to disappear, necessitating special consideration of the social environment of black Americans living with the virus. This creates a unique situation for those living their lives with this stigmatized illness, especially for women in the realm of sexuality and romantic relationships. Because 85 percent of black women contract the virus via heterosexual contact, it is safe to assume that sexual behavior is common among the majority of black women (CDC 2011a). This section looks at literature pertaining to sexuality following diagnosis, and focuses mainly on black women, although much of the literature cited includes the experiences of women of many ethnicities, not just African American women.

As previously mentioned, HIV/AIDS is undoubtedly a highly stigmatized illness (Black and Miles 2002; Kalichman and Nachimson 1999; Sowell et al. 2003). Being diagnosed as HIV positive often conjures up images of “socially deviant” persons—those involved in sex work, promiscuity, or injection drug use (Sandelowski et al 2009:273), and marks these women as “dirty, diseased, and undeserving” (Lawless et al. 1996:1371). Many black women already feel they suffer from “multiple sites of oppression” as both a female and a person of color (Berger 2004:19), and being HIV positive adds an additional layer of marginalization (Sandelowski et al. 2009). Stigma is also associated with increased psychological distress, including depression, a topic of special concern for persons living with HIV/AIDS, (Catz et al. 2002; Clark et al. 2004). Various studies

demonstrate elevated rates of depression in samples of sero-positive African American women specifically (Catz et al. 2002; Lichtenstein et al. 2002; Vyavaharkar et al. 2011).

Living with a stigmatized disease and with the possible discrimination it entails creates a variety of negative outcomes. A study by Buseh and Stevens (2006) looks at the intimate experiences with stigma of 29 African American women. Stigmatized attitudes and actions were present in interpersonal relationships and institutional settings alike, and many women reported internalizing the stigma they experienced. Upon initial diagnosis, the women participated in self-blame, often alongside feelings that the lives they had prior to diagnosis were over and that death was imminently approaching (Buseh and Stevens 2006). Those who knew about their status, even members of their families, treated them like “outcasts,” unwilling to touch them due to being misinformed about HIV’s transmission (Buseh and Stevens 2006). Within settings intended to provide aid, such as welfare offices or health care settings, women were mistreated or even ignored due to their HIV status (Buseh and Stevens 2006). In response to the stigmatization and discrimination, women found resilience through seeking support, prayer, refusing to accept someone else’s ignorance about the disease as their own problem, disclosing strategically or most dramatically, becoming disease advocates (Buseh and Stevens 2006).

Black women are said to utilize religion and spirituality as a common coping mechanism following their diagnosis (Hickman et al. 2012; Morse et al. 2000; Tufts et al. 2010). A qualitative study of self-care behavior among HIV positive African American women (n=21) found that in addition to religion, women coped with their infections by boosting their social networks with supportive individuals and organizations, focusing on

taking care of their bodies and maintaining sobriety, and following their doctors orders for healthy living (Tufts et al. 2010).

HIV and Relationships

This section will discuss women who deny their infections altogether, those who feel they are unable to pass their infection to others, and those who choose celibacy as the most viable option for sexuality following their diagnosis. Literature concerning women who remain sexually active will be presented as well. Among women who do choose to continue sexual activity while living with HIV, aspects of their experiences with sexuality, including fear of further transmission, the challenges of consistent condom use, and disclosure patterns, will be discussed.

Just as the denial of risk of initial HIV infection exists among many black women researched by Sobo (1995), some will deny their HIV infection altogether, simply pretending it is not there or refusing to believe they are positive and then engaging in unprotected sexual activity (Gorbach et al. 2004; Leserman 2000; Reeves et al. 1999). Similarly, some adopt a “don’t ask, don’t tell” attitude whereby if their partner does not request a condom or inquire about HIV status, the positive partner feels they have been relieved of their responsibility to disclose their status or to insist upon safe sex practices (Bairan et al. 2007; Marks et al. 1999).

Though advances in medications are drastically extending lives of those living with HIV infection, the use of such therapies may lead some to believe they are no longer able pass the virus onto others (Crepaz et al. 2004; Marks et al. 1999; Wilson et al. 2004). Antiretroviral therapy (ART) lowers HIV viral loads until they are “undetectable,” meaning there are very low levels of the virus in the blood. While the chance of passing

HIV to others is significantly lower with an undetectable viral load resulting from strict adherence to ART, it is possible to acquire a secondary infection, either with other strains of the virus or with other STIs, which may quicken HIV progression (Marks et al. 1999). Re-infection with HIV also raises concerns over drug resistance (Smith et al. 2005; Wilson et al. 2004). When an infected individual is resistant to one more or drugs, they pass their resistances along with their infection, widening the pool of resistant mutations (Little et al. 2002). This type of “super-infection” can leave individuals resistant to multiple drug combinations (Kalichman et al. 2010:2), which limits their drug treatment options and lessens the effectiveness of a drug, allowing their health to decline more rapidly than if they had no drug resistance (Little et al. 2002).

Celibacy After Diagnosis

Some HIV positive individuals do swear off sex forever following their diagnoses, with anywhere from 32 percent (Hankins et al. 1997) to as high as 78 percent (Siegel and Scrimshaw 2003) of HIV positive women identifying as celibate following their diagnosis. A study among HIV positive injection drug-using women found that around a third “avoided” sex altogether (Meyer-Bahlburg et al. 1993), while Bova and Durante (2003) found that 42 percent of their sample (n=101) had not engaged in sex within the previous month.

Siegel and colleagues (2006) compared sexual functioning, desire, and satisfaction between two groups of women (ages 20 to 50) both before Highly Active Antiretroviral Therapy (HAART) in 1994 and 1996 and after in 2000 and 2003. No significant differences existed between pre and post HAART, but three themes emerged from their interviews. Women reported experiencing less pleasure from sex, participating

less in sexual activity, and feeling less sexually attractive (Siegel et al. 2006). Around one third (33 percent) of those interviewed reported experience with one or more of these issues (Siegel et al. 2006). The women who were celibate expressed a desire to protect themselves emotionally; getting close to someone would require them to disclose their status thereby opening themselves up to rejection (Siegel et al. 2006). For women, the prospect of pursuing a man and then having to tell him they are HIV positive produced “overwhelming” fear and anxiety, leading these women to “preserve their sparse emotional resources” and simply remain alone, as dating was seen as a “hassle” (Siegel et al. 2006:444). Their feelings of sexual attractiveness had dwindled, leaving one woman to state she felt like a “walking, friggin’ germ,” suggesting if men knew her status they “wouldn’t want to have shit to do with me anyway” (Siegel et al. 2006:446). Siegel and colleagues report that most celibate participants did not miss having sex, and some even associated their infection with their previous sexuality, feeling it should be repressed now for getting them infected in the first place (2006).

Subjective Experiences of Sex While Positive

Among the women interviewed by Siegel and colleagues who did remain sexually active following their HIV diagnosis, sex and relationships changed considerably. Even with the use of condoms, women worried they would transmit the virus to their partner, whether it be through a break or a hole in the condom, or if it slipped off (Siegel et al. 2006). This made them “uptight” and “uncomfortable” during sex, resulting in a less satisfying experience (Siegel et al. 2006:442). Most poignantly, one participant said: “Ah, it’s just always in the bedroom, HIV. It’s always there” (Siegel et al. 2006:442). A loss of spontaneity was also reported by women, who felt that the need for condoms and

the loss of intimacy created by their use hindered their ability to enjoy sex, which suddenly turned into a “chore” (Siegel et al. 2006:447). The need for disclosure and condoms created sexual inhibitions they had not experienced before. Two participants specifically noted missing having their partner perform oral sex on them, one of the only ways they were able to experience orgasm (Siegel et al. 2006).

Women from an Ontario and Nova Scotia based study reported similar themes of a loss of spontaneity and of their former sexual self, as well as fears of disclosure. Some felt that their HIV status took a sexual “power” from them that they once had, and to disclose their status was a complete release of their agency altogether (Gurevich et al. 2007:20). Their former ability to engage in spontaneous sex without their minds cycling through what responsible or rational choices are, and discussing safer sex had been “constrained” by HIV (Gurevich et al. 2007:18-19). Condoms carry meaning suddenly, more than a precaution, they become a literal barrier of the disease, creating an awareness of the reason the condom is there (Gurevich et al. 2007). For HIV positive women, to disclose their status places them in a catch 22 of sorts—they have fulfilled their duty protecting the safety of their partner, yet worry once they admit their status they will be labeled as “promiscuous” or a “hooker” (Gurevich 2007:19-20). Others worry that once their partners know about their status, the sense of eroticism and sexual desire will fade into illness and caregiving; the title of “sexually desirable woman” will be replaced by “a walking, talking virus, neither fully sexual nor fully human” (Gurevich 2007:21). Even their flirting became inhibited, fearing it may lead to something more and will eventually require them to disclose (Gurevich 2007).

Rhodes and Cusick (2000) found that among sero-discordant couples in the UK, sex became a balancing act where couples struggled to maintain “relationship security” at the same time as “viral protection,” which resulted in contradictory and anxiety-ridden decisions (8). Unprotected sex signaled intimacy and emotional closeness, with condoms less likely to be used as the relationship progressed to be more serious (Rhodes and Cusick 2000). To go without a condom was a sign of relationship strength and commitment, with one HIV negative participant even claiming he eventually felt “obliged” to have unprotected sex with his girlfriend, “to show how much I love her” (Rhodes and Cusick 2000:9). As discussed elsewhere by an HIV positive respondent (Gurevich et al. 2007), the physical barrier created by condoms is a constant reminder of their infection: “Although you’re as intimate as you can be, there is still a piece of latex between you, and I know that sounds really pathetic, but you know, it’s a consideration” (Rhodes and Cusick 2000:9). As condoms are used less and less, authors state, unprotected sex becomes “less of a denial of viral dangers” and more of an “acceptance of danger as a part of love and life” (Rhodes and Cusick 2000:12). On this same vein, some felt that contracting HIV from their partner was inevitable, just a part of being together and entirely committed to their partner, and worth the risk to go without condoms (Rhodes and Cusick 2000).

Status Disclosure

Disclosing one’s HIV status can be emotionally challenging, even to those other than potential sexual partners. Serovich and colleagues (2008) suggest a “consequences-based model” is most frequently used among HIV positive women, which involves a weighing of disclosure costs and benefits to aid in decision-making (24). This type of pro

versus con technique was also found by Sowell and colleagues (2003) in addition to disclosing on an “emotional” or “intuitive” basis, where a woman felt the time was right, that it was the right thing to do, or sensed a person trustworthy (39).

It should be noted that Florida is one of 37 states that makes failure to disclose one’s HIV status to sexual partners a criminal act, even if there is no viral transmission (Kaiser Family Foundation 2010). In Florida, it is considered a third degree felony to have oral, anal or vaginal sex with someone who is unaware of their partner’s being HIV positive (Florida State Legislature 2012a; Kaiser Family Foundation 2010).

Literature concerning status disclosure has resulted in a variety of disclosure patterns and rates. Sowell and colleagues (2003) conducted a study with 322 women, predominantly African American (88 percent), and found that most had disclosed to someone, with only 3.8 percent of participants having told no one of their status. Among women who disclosed, over three quarters (78.3 percent) disclosed rather quickly, within the first week of their diagnosis (Sowell et al. 2003). Those most frequently told within this week include parents, partners, siblings, friends and children (Sowell et al. 2003). Interestingly, 65.4 percent of women reported disclosure to all of their sexual partners (Sowell et al. 2003).

Similarly, a 2003 study by O’Brien and colleagues found that their participants (n=269, 47.6 percent female) tended to disclose more frequently to “main partners” (74.2 percent) and “immediate family members” (69.8 percent) at higher rates than they disclose to casual sexual partners (about 24.8 percent). Authors note that women were more likely to tell non-immediate family members more often than men (O’Brien et al. 2003).

Disclosure is inherently challenging because of the uncertainty it holds, though sharing one's status is the only mechanism for accessing some of the potential positive outcomes that exist (Clark et al. 2004; Smith et al. 2008). Most notably, social support is a benefit of status disclosure widely discussed as an often-lacking necessity to those living with this chronic condition (McDowell and Serovich 2007; Serovich et al. 2008; Smith et al. 2008; Vyavaharkar et al. 2011).

Social support comes in four forms, emotional, instrumental, informational, and appraisal (Heaney and Israel 2008). Emotional support is demonstrated through empathy, love, trust, and care. Instrumental support provides services or tangible support, such as financial assistance (Heaney and Israel 2008). Information support is shown through advice giving, information, or idea sharing (Heaney and Israel 2008). Finally, appraisal support is meant to provoke self-reflection or re-evaluation (Heaney and Israel 2008). Each type of support is meant to be a positive influence in one's life and is most beneficial when it comes from varying individuals or groups and from multiple social networks (Heaney and Israel 2008).

Unfortunately, women disadvantaged by a low socioeconomic status (SES) and living with HIV may be doubly lacking in terms of social support (Edwards et al. 2012). In addition to suffering from stigma, the "similar life situations" of other low SES individuals around them may limit their ability to offer social support, especially in terms of tangible (i.e., financial) or informational support (Edwards et al. 2012). Accordingly, high SES individuals are more likely to report greater social support than those of low SES backgrounds (Edwards et al. 2012). On a more positive note, McDowell and Serovich (2007) corroborated earlier studies which suggest the *perception* of social

support may be more beneficial than actual support, still contributing to the desirable outcomes of social support including better medication adherence (Edwards et al. 2012). Among HIV positive individuals, risking the negative outcomes of disclosure does open the possibility of receiving any type of support.

As will be discussed in the following sections, the decision to disclose is influenced by many variables, including who is to receive this information, and what is at stake in telling them.

Disclosure to Children

For some mothers, the decision to inform their children of their HIV status is understandably frightening. A 2008 study found that women (n=66, 71% African American) who do decide to share their HIV status with their children are mainly motivated by feeling as if the child has a right to know, wanting to avoid the child finding out from someone else, and the desire to ensure the child feels comfortable with the information (Delaney et al. 2008). Alternatively, women who avoided telling their children felt it may be too much of an emotional burden on them, causing fear or worry, and accordingly felt their children deserved a life without that knowledge (Delaney et al. 2008). Pilowsky and colleagues (2000) found similar reasoning for (non)disclosure for African American and Latina mothers in New York City (n=29). Their study revealed that 59 percent of women had not disclosed to their children (Pilowsky et al. 2000). Again, feeling disclosure was “right to do,” some mothers also saw revealing their status as a step towards preparing for the child’s future in the case of their mother’s untimely illness or death (Pilowsky et al. 2000:728). In addition to avoiding overloading children with emotional pain (Delaney et al. 2008), some chose against disclosure because of

nature of the topic, mainly “death and dying,” and fear that the children may not understand (Pilowsky et al. 2000:729).

In respect to timing of disclosure to children, a study by Armistead and colleagues (2001) founds that among a sample of 87 African American women living with HIV, only 30 percent had chosen to disclose to their children, and tended to do so very soon (“within a few days of diagnosis”) or after a year or more (18). Those with lower incomes were found to disclose more frequently than those of higher SES, suggesting limited access to childcare may mean children will accompany mothers to doctor appointments, and must be informed of their mother’s situation (Armistead et al. 2001). Lastly, neither length of time since diagnosis nor stage of illness (defined as “asymptomatic,” “symptomatic,” or “AIDS”) were associated with likelihood of disclosure to children (Armistead et al. 2001).

Disclosure to Sexual Partners

The most commonly cited reason women fail to disclose their status is because they fear rejection of others, including sexual partners, family, and friends (Black and Miles 2002; Kalichman and Nachimson 1999; Sowell et al. 2003). Rejection could mean a loss of a romantic or sexual relationship, abandonment or a loss of social support, which is often desperately needed in this situation of vulnerability (Greene and Faulkner 2002; Kalichman and Nachimson 1999). Literature suggests women’s fear extends beyond potential rejection from their sexual partners upon disclosure; some anticipate their sexual partners will not respect the confidentiality of this information, threatening other interpersonal relationships with friends and family members (Black and Miles 2002). Studies also show that nondisclosure is more common with casual partnerships,

such as a one-night stand, where women felt there was little hope for a future relationship (Bairan et al. 2007; Marks et al. 1999; Sobo 1995). For many, disclosure of a positive status means admission of “socially unacceptable practices” such as injection drug use, casual sexual relationships, or sex work, whether past or present (Sobo 1995:54), and facing adding an additional “layer” of stigma to their already damaging diagnosis (Sandelowski et al. 2009).

A 1999 study by Kalichman found that status disclosure among HIV positive individuals (n=203 men, n=129 women) was inconsistent at best, with slightly more than half of men and less than half of women having had engaged in a sexual activity without disclosing their status to a partner (Kalichman 1999). Further, of those reporting having unprotected sex within the previous six months, 25 of 35 women and 28 of 49 men did not disclose to partners (Kalichman 1999).

Sero-concordant Sex

Some HIV positive individuals may choose to have sex with another sero-positive person, which may create an imaginary safety net because both partners are positive (Catz et al. 2001; Kalichman 2000; Marks et al. 1999), although the possibility of re-infecting their partner with another strain of the virus is still a threat. Concordant partnerships create a “relative safety,” (Rhodes and Cusick 2000:19) whereby the risk or reinfection is notably lower because antiretroviral treatment is effective in suppressing the amount of virus in one’s blood. In addition to feeling it less necessary to use condoms or other barrier methods (Catz et al. 2001; Kalichman 2000; Marks et al. 1999), some individuals may feel they are not as likely to be rejected, and may gain empathy and emotional closeness due to a shared positive serostatus (Frost et al. 2008).

Sero-concordant couples interviewed by Rhodes and Cusick (2000) used infections as a way to justify unsafe sex, not just because they believe they were unable to pass the virus to someone else, but for emotional reasons as well, as one of them states: “It made you feel normal to be able to sleep with this person without a condom” (19). Relations with a sero-concordant partner allowed for a “release” from the “anxiety” of sex with someone HIV negative and offered an increased degree of comfort to find someone that empathized with their experience living with HIV (Rhodes and Cusick 2000). Those who purposefully sought out an HIV positive partner made them “active agents” in their relationships, in which the management of risk was much simpler (Rhodes and Cusick 2000:20). None of the 11 participants who sought sero-concordant relationships reported using condoms (Rhodes and Cusick 2000).

Condom Use and Non-use

As previously mentioned, condoms are the most commonly promoted method of HIV prevention, yet much of the time they are not utilized, even with awareness of a positive status. Bova and Durante (2003) interviewed 101 HIV positive women and found that a third of sexually active women did not make use of condoms or other safer sex practice after their diagnosis. Nearly one quarter of women in a Montreal-based HIV study reported never using condoms after their diagnosis as well (Hankins et al. 1997). This pattern has also been illuminated within the United States (Ciccarone et al. 2003; Gielen et al. 2000; Sobo 1995). In addition to the intrapersonal factors mentioned above, partner refusal is frequently discussed as the major reason couples fail to use condoms as protection during sex (Hankins et al. 1997; Stevens and Galvao 2007). Dislike of condoms is well established among both males and females, as condoms are often said to

make sex less “natural” or “pleasurable” (Junge 2002:203) or described as “nasty” (Sobo 1995:166). Higgins and Hirsch (2008) interviewed 36 HIV negative men and women in Atlanta (about half of whom were persons of color) and found that in this case, more women than men were resistant to condoms due to physical sensations and discomfort. Women reported problems with dryness, experienced lessened sensation, or had a desire to have skin-to-skin contact with their partner and to have their partner ejaculate in them (Higgins and Hirsch 2008). Condoms are also said to disrupt the sexual experience by eliminating sexual spontaneity that comes when forgoing condom use (Higgins and Hirsch 2008; Keegan et al. 2005)

Condom negotiation can also be challenging for some, especially in the context of a relationship. Many black women who request condoms can be perceived as being too forward or as having an STI (Bowleg et al. 2011; Whitehead 1997). Whitehead’s (1997) black male participants furthered this notion by claiming women who were willing to put the condom on a man were said to “sleep around” or being “too schooled’ sexually” (416). Again, asking for the use of condoms may signal infidelity or mistrust of their partner, especially within monogamous relationships (Singer et al. 2006; Small et al. 2009).

Other reasons for engaging in unprotected sex exist as well. A study by Stevens and Galvao (2007) tells the stories of ten HIV positive women whose partners refused to wear condoms, despite knowing their wife or girlfriend was HIV positive. Interviews were conducted over a two year period, allowing interviewers to form relationships with these women, who slowly revealed that their partners’ refusal to wear condoms was a source of contention and caused arguments within the couple, until the women eventually

conceded to sex without condoms in order to maintain peace (Stevens and Galvao 2007). Within these stories, women take a submissive role, a few admitting they were just happy that someone was willing to love them in spite of their HIV status, as one of them stated: “Because he wants sex without a condom and he knows I have HIV, that’s the reason I know he loves me. And that is all I ever wanted in a man, to feel that way about me” (Stevens and Galvao 2007:1019). Men, on the other hand, felt that they were not susceptible to the infection, or felt that if it were to happen, it was part of God’s plan (Stevens and Galvao 2007). Dislike of condoms was common as well, with men reporting a loss of sensation, and at times even appearing controlling. One female participant stated “He is obsessed with me. He says if he can’t have me, no other man can. It’s the thought of taking control of my body, that’s why he won’t use a condom” (Stevens and Galvao 2007:1019). Due to their partners’ unwillingness to wear condoms, these women felt immense guilt and fear that they would pass the virus on, carrying a “heavy burden” knowing they could be responsible for endangering someone they cared for (Stevens and Galvao 2007:1019).

FINAL THOUGHTS

While poverty worsens susceptibility to HIV for all those living under its constraints, the conditions unique to black Americans—unequal sex ratios, increased rates of incarceration, and gender role expectations--are what set them apart from other ethnicities in terms of “risk.” Specifically, the interplay between black male removal from society through high rates of incarceration severely impacts the gender roles and how men and women interact. Women who value being in a relationship have a limited number of viable options, particularly if they are being selective according to Sobo’s

(1995) wisdom narrative. Men, in response to their inability to advance sociopolitically due to historical impediments (Whitehead 1997), may be encouraged to take advantage of their scarcity through risk-increasing concurrent relationships (Morris et al. 2009) with women who desire the self-esteem building benefits of a man (Sobo 1995).

Once a woman is living with HIV, the need to disclose and potential rejection they face adds another layer of vulnerability within a relationship, placing a woman at a disadvantage in terms of power negotiations, as evidenced by Stevens and Galvao (2007). In sum, though the influential factors are numerous, the circumstances that are specific to the black community, African American male incarceration, unbalanced sexual ratios and gender role expectations, are likely to contribute heavily to the disproportionate rates of infection.

CONCLUSION

This section has provided the background literature pertaining to why African Americans are becoming infected with HIV at a rate much greater than other groups in the United States. Societal level influences, including poverty, structural violence, discriminatory practices, lack of health insurance, and fewer housing and employment opportunities create an environment which increases risk, especially when coupled with elevated rates of incarceration, unequal sex ratios, stigma and gender role expectations which hold men and women to standards that may put their health in danger.

After women are diagnosed with HIV, their lives continue to be plagued by stigma, discrimination, and shame. Coping often involves religion, social support, and a focus on good health. When it comes to disclosure, denial, fear, and shame influence whether their partners are informed of their status and whether condoms are used.

Additionally, an examination of their subjective experiences including their enjoyment and pleasure from sex and changing definitions of intimacy has been provided. Many of these themes will arise in Chapter 4 in the discussion of interview results.

Chapter 3: Methods

INTRODUCTION

The purpose of this chapter is to outline the methods used to collect and analyze data collected during my time spent at Francis House, a non-profit organization located in Tampa, FL. A description of the research goals and the site where data were collected will be provided. Then, the methods utilized will be discussed, and include participant observation, a brief questionnaire and semi-structured interviews. A reflexive discussion of rapport building, and how this may have been influenced by my positioning and privileges as a white researcher among black participants, will follow. Finally, the chapter will end with an explanation of data analysis.

RESEARCH QUESTIONS

The purpose of this study was to explore the ways in which HIV positive black women, a group disproportionately affected by the virus, navigate their sexual and romantic lives following their diagnosis, in order to understand the women's condom use, disclosure patterns, definitions of intimacy, and general experiences with sexuality. The following research questions guided the methodological choices and data collection:

- How does an HIV infection affect the experience of sex, intimacy, and relationships among HIV positive black women and their partners?
- What factors --at both micro and macro levels- -influence HIV positive black women's decisions to disclose their HIV status to their sexual partners?

- How are safe sex practices negotiated, if at all? Do they differ depending on the sero-status of their partner(s)?

RESEARCH SETTING

After being turned down by an alternative local AIDS service organization in Tampa, I contacted Francis House in March 2012 after seeing their name listed as a potential location for College of Public Health students to complete their required Field Experience. Joy Winheim, Executive Director, agreed to allow me to spend time in the facility as well as to collect the data I desired. Beginning in May of 2012 and ending in late August, I spent between 10 and 15 hours per week at Francis House. From August until November I occasionally returned to spend time with clients I had come to know, usually once every two weeks.

Francis House, a non-profit organization serving those infected and affected by HIV/AIDS, is located in Tampa, Florida. Open since 1990, Francis House is founded upon the principles and teachings of St. Francis of Assisi, emphasizing “compassion, individual responsibility and accountability” (Joy Winheim, personal communication, February 26, 2013). Francis House provides free case management, housing assistance, daily support groups and hot lunch, food bank, mental health and substance abuse counseling and HIV/AIDS educational services to around 300 clients per year. Ninety percent of funding is federally granted, with sources including Housing Opportunities for Persons with AIDS (HOPWA), Ryan White Part A and General Revenue, with the other portion of funding from the Hillsborough County Family and Aging Services and the Fred B. Sieber Foundation (Joy Winheim, personal communication, February 26, 2013). Unlike other AIDS service organizations (ASOs) in the Tampa Bay area, Francis House

prides itself on offering more “holistic” care, where more services in one location minimizes the chance that clients will “fall through the gaps” (Joy Winheim, personal communication, February 26, 2013). Francis House is the only ASO in the area that provides breakfast, lunch and free bus passes to clients.

In order to take advantage of Francis House services, clients must be referred from another care provider in the community, including ASOs, physicians and other social service organizations. They are required to provide proof of their HIV status and income, and once established as a client, there is no limit to the services they are able to receive, though this is often limited by budgetary considerations (Joy Winheim, personal communication, February 26, 2013). There are other ASOs in the area that Francis House clients use as well. Services provided by Francis House are focused on Hillsborough County, though most clients are from the city of Tampa due to transportation limitations in more distant areas (Joy Winheim, personal communication, February 26, 2013).

Clients’ age ranges from 19 to 77 years, and it is estimated that about half of clients are African American (Joy Winheim, personal communication, March 12, 2012). However, the on-site observations carried out as part of this research suggest that the proportion of African Americans may be closer to 70 percent. The gender distribution is estimated to be around 30-40 percent female and 60-70 percent male (Joy Winheim, personal communication, February 25, 2013). Clients are free to bring their family and friends to Francis House (these individuals would be described as “affected by HIV”), but these uninfected individuals must go through registration process to become a client in order to attend support groups, or receive other benefits available at the facility. When

Francis House hosts “Lunch and Learns,” which occur two to three times per month, the outside public is welcome to attend.

Clients generally begin arriving at Francis House as soon as the doors are unlocked, around 8:30 AM. A large multi-purpose room houses tables arranged in a U-shape, creating an almost classroom-like feel when clients face the leader of the daily support group, which begins at 11 AM and lasts one hour. Following what clients simply call “group,” is lunch, prepared by a full time employee and three men who volunteer their time in exchange for “Francis House Dollars,” a way to “purchase” food from the in-house food bank or to do laundry on site. All clients are able to earn Francis House Dollars and take advantage of the laundry and food bank, which is stocked through donations and monthly allotments of federal funding. Francis House Dollars are given for attendance of support groups (two dollars), individual counseling sessions (three dollars), cleaning or cooking (eight dollars per hour), or other odd jobs, such as unloading food bank deliveries (dollar amount varies).

Prior to group, clients can be found drinking heavily creamed and sugared coffee out of plastic Olive Garden cups and mismatching coffee mugs donated by community members, while watching The Jerry Springer Show, socializing, reading the Bible, gossiping, telling jokes, leafing through the daily *Tampa Bay Times* newspaper or sitting quietly by themselves. A picnic table and plastic lawn chairs remain full in the fenced-in area designated for smoking adjacent to the front door. Because the majority of clients utilized the local bus service as primary transportation, Francis House quickly empties after lunch, with only a handful of people still hanging around after 1:30 PM.

Francis House clients and staff alike describe themselves as a family. They claim to all love and care about one another, but just like all families, they do fight. Over my time spent there, I witnessed disagreements and expressions of frustrations with one another, and was privy to a great deal of gossip. Ultimately, clients tended to stick up for one another during times of need (i.e., roommate problems, a housing crisis, death or loss of relationships), but a certain level of animosity amongst particular clients was evident. The staff always remained objective, ensuring no one client was alienated or bullied by the others.

Building Rapport

I felt I had to tread lightly during the first few days of research at Francis House, making sure to be the first to extend my hand in introduction. Though most clients were unafraid to forcefully address a newcomer into their territory, I hoped to maintain transparency from the start. Unfortunately, like Checker's (2005) participants who were living among dangerous environmental toxicants in rural Georgia, Francis House clients were not quite "sure why I was there, what I planned to do, or how long I planned to stay" (193). The field of anthropology was new to Francis House clients and staff alike, and I found the discipline was often difficult to explain succinctly, especially in relation to my research questions. Contrary to Checker's experience, Francis House staff members represented a number of varying ethnicities and cultures, making me one of multiple white employees and volunteers. There were times I felt my race, based upon my outward, phenotypic traits of being white, was more or less influential than others though; informal interactions, such as prior to and during support groups, my being a white researcher studying black participants was less striking than it was during one on

one interviews, as there was a variety of ethnicities and skin tones seen amongst staff and clients in group settings. I rarely felt race created a divide or tension among Francis House clients themselves, perhaps because their HIV infection was a leveling factor and allowed for some amount of coexistence.

Unlike most volunteers who spent the sweltering summer days at Francis House, I opted to sit around with the clients, getting to know them, instead of sitting behind the front desk of the facility. The front desk, with strict rules that no clients were allowed behind, tended to create a division of power between clients and volunteers, who were seen more as part of the staff and tended to have more social distance from the clients. I sat amongst clients during group and lunch as well, hoping to demonstrate that though I was clearly an outsider, I wanted to understand their point of views as closely as possible. I asked questions about their families, looked at pictures of their children, and listened to what was on their minds at the time. There were times when I assisted a woman taking a GED course with challenging math problems, or helped translate a confusing legal document for a man trying to reinstate his driver's license. My time spent "hanging out" was the most useful time in terms of rapport building, and allowed me to demonstrate my trustworthiness and loyalty to these individuals (Bernard 2006:368). Over time, the clients came to view me as someone who was not quite a staff member, but someone not quite a client, either. This state of liminality, of being "betwixt and between" a distant, power-wielding staff member and a friend of clients (Turner 1987:5), was satisfying though, because as I will discuss, being in a position of privilege created obstacles to overcome before even beginning my research.

A Note on Privilege and Positionality

In her discussion of the myth of objectivity within the social sciences, feminist Donna Haraway (1988) states “only partial perspectives promises objective vision” (583). In my case, not only did my “race” separate me from my research participants, but so did my education and my middle class upbringing. These accorded me a different “social position” than that of the Francis House clients of all ethnicities (Duneier 1999:352). Many clients had less than a high school education, lived below the poverty line, relied much more on heavily on public transportation and services than I did, including health care coverage, financial assistance and food stamps. Being that this was my first experience spending a great deal of time getting to know others who were not within the socially safe area of my “upper-middle-class whiteness,” I became more and more aware of the “blindness I might have to the circumstances of people who are very different from me” (Duneier 1999:353). For example, of the nine women I interviewed who were infected with HIV via sexual contact (one participant was perinatally infected, and will be excluded from my analysis), eight had previously struggled with drug or alcohol addiction and had engaged in sex for drugs, money or other goods. This reality forced me to confront circumstances I had never considered—that addiction or poverty could bring someone to such dire conditions that they would utilize their body and informal networks to obtain what they needed. What I had always heard of growing up as a form of prostitution was a viable, and fairly rapid method of obtaining what was needed. And while this was a challenge to the norms of life that are familiar to me, it served as a

reminder of how my background is always with me, no matter how much anthropology challenges me to disrupt stereotypes.

When planning and conducting research at Francis House, specifically among black women, the issue of my racial difference cannot be left unmentioned. I wondered: Would these women feel comfortable enough to discuss their stigmatized illness with me? Moreover, would they tell me how this disease had impacted a very personal aspect of their lives--their sexuality? While I do believe my ability to relate as a woman was an advantage, like Duneier (1999) states in his discussion of being a white researcher amongst black participants, “it would be naïve for me to say that I knew what they were thinking, or that they trusted or accepted me fully” (339). I must be realistic, realizing that I could have been receiving modified truths, because “as a survival mechanism, many blacks still feel that they cannot afford to speak honestly to whites” (Duneier 1999:338). This is one instance where my “white privilege” may work against me (McIntosh 1988); I must respect the historical truths that black and white tension is deeply rooted and continues to exist.

Certainly I will never understand what it is like to live life as a black woman, nor do I currently understand what it is like to face every day as a woman living with HIV, but through my life experiences with common human emotions—pain, sadness, heartache, for example—I attempted to provide a understanding ear for the women who bravely shared with me. To this extent, my authority as a researcher was impossible without participant willingness, a point I must not neglect. Feminist Judith Stacey (1988) believes women are well suited for ethnographic studies because of their aptitude for “empathy, connection, and concern” (22). But empathy can only take a researcher so

close to complete trust and acceptance by participants; because I was simply a visitor at Francis House and did not live in the same circumstances as many of the individuals with whom I spoke, I was “far freer to leave” the situation than clients (Stacey 1988:23). Whether this was explicit or not, it could have created a sense of distance between participants and me.

As I have discussed, my positioning as a student researcher is not without influence from my race, privilege, education, and upbringing. Further, my view of the HIV/AIDS epidemic among black Americans is not without politically, environmentally, socially, and economically situated understandings, based upon my review of existing literature which supports a number of macro level causes. This is a true “privilege” of being within academia—I am able to “spend time articulating and working through understandings that others engaged in immediate practice pursuits often necessarily leave more tacit” (Calhoun 2008:xxii). With this privilege, comes “responsibility to make scholarly contributions,” an idea which is especially central to my identification as an applied anthropologist (Calhoun 2008:xxii). And while many anthropologists are discouraged from becoming too involved in changing the world around them, concerned that making “political alignment explicit” may “undermine scholarly rigor,” I believe a health disparity of this magnitude cannot be ignored in the hopes that I may be able to maintain at least partial objectivity (Hale 2008:2-3).

METHODS

The methods used to collect data were participant observation, a questionnaire and semi-structured interviews. These will be described in greater detail alongside participant eligibility criteria and recruitment strategies.

Eligibility Criteria

The criteria set for participation in this research included: 1) being female, 2) being HIV positive, 3) identifying as black or African American, 4) being between the ages of 18 and 64 years, and 5) having taken a new sexual partner within the last five years. The final criterion, the number of years since having taken a new sexual partner, was originally stated as two years, but needed to be extended during the final portion of data collection due to difficulties in acquiring enough participants. In the end, women who had taken a new sexual partner within the past five years were eligible for the interview.

Participant Recruitment

Recruitment of participants took place during the time before group and during lunch. After receiving approval from the University of South Florida Institutional Review Board to begin conducting research, I approached the women who appeared to be African American, describing my research and determining their level of interest. Because I spent two days a week for a month at Francis House engaging in participant observation and getting to know the clients before recruitment began, most of the women I approached were aware of my purpose at the facility. Many approached to participate and screened via the questionnaire were ineligible to participate due to either their lack of sexual activity following diagnosis, or more frequently, because of the length of time it had been since they had taken a new sexual partner, which was often longer than five years. Because of these reasons, and relatively small pool of African American women who attended Francis House during the hours I was there, the sample size is small (n=9). Four case managers at Francis House, who knew of women who attended infrequently or

on different days than I was there, were contacted as an additional measure to recruit. Unfortunately, these efforts were not fruitful.

Those who were ineligible for participation had their questionnaires immediately discarded; the completed questionnaires of those who continued on to the interviews were stored. The background data they provide are presented in Chapter 4. Quickly after I began recruitment, women began to approach me to participate, likely due to the incentive of 20 Francis House Dollars upon completion of the interview. Francis House Dollars could be used in the on-site food bank, where all items cost one Francis House dollar. These items included cereals, canned goods, pasta, and other foods, as well as other household items such as toilet paper, laundry detergent, toothpaste, and cleaning supplies.

Participant Observation

Participant observation occurred while clients socialized at the facility, during informal conversations, while sitting in on the daily support groups including Relapse Prevention, Spirituality, Topic of the Day (whatever topics the clients had on their minds that day), Lunch and Learn (where outside speakers, including physicians, pharmaceutical company representatives, and health educators, provide information and a catered lunch to clients), and during the hot lunches which were served daily at Francis House. Generally, I attended Francis House on Tuesday and Thursday, from 8:30am until 1:30pm, which is also the time the most clients are in attendance. My time was spent talking and visiting with clients, helping in the kitchen with dishes or lunch preparation, talking to staff members behind the front desk, and assisting with occasional tasks such as stuffing envelopes for a fundraising campaign, unloading a food pantry

shipment, or ensuring there was always enough coffee made. On Tuesday and Thursday, support group themes were on “Relapse Prevention” and “Spirituality,” respectively, presenting me with two very different types of discussions to observe. The former, certainly more popular than the latter, centered around an organic discussion of recent drug or alcohol relapses, struggles to remain clean, and sharing of personal accounts of successful sobriety. Spirituality tended to be more directed, providing inspirational quotes to be discussed or synopses of self-help books about seeking happiness and self-fulfillment.

A small notebook to record field notes was utilized during support groups, but rarely outside of this time as I did not want to make clients uncomfortable. While they were aware of my purpose for being there, to collect data, the semi-structured interviews were the primary method used to collect the bulk of my data. Field notes taken during support groups are used to paint a picture of what Francis House clients do with their time there, as well as that illustrate the conversations that naturally arose before and after group, which were later recorded from memory after leaving the field site.

Screening Questionnaire

The informed consent document was provided to potential participants prior to administering the screening questionnaire. Women were instructed to read the form, taking as much time as necessary, and approach me once this was completed and they agreed to its terms. Most women quickly read over the form while at Francis House. Because Florida law dictates a third degree felony for individuals who fail to disclose their HIV status to a sexual partner prior to intercourse (Florida State Legislature 2012a), and due to the sensitive nature of the information I would be discussing with them,

participants did not sign a consent form, instead consented verbally. All data collected are completely anonymous, with no information recorded which could potentially lead back to the participant. The anonymity of this study not only allowed for a less inhibited dialogue between participants and me, but it also eliminated any requirement to report any women who might reveal their sexual activities with uninformed partners. All participants were provided a chance to ask questions or to clarify the informed consent document.

Questionnaires were completed in a small, private office with the door closed. To better facilitate questionnaire administration, I provided the potential participant with a copy of the questions I would be asking, allowing them to follow along. Basic demographic information was collected including age, date of birth, ethnicity, education level, years since diagnosis, method of HIV transmission, a subjective assessment of their current mental and physical health statuses, and questions to assess how recently they had taken a new sexual partner. This questionnaire can be seen in more detail in Appendix A.

Upon completion of the screening questionnaire, which took less than five minutes, women were told of whether or not they were able to participate in the semi-structured interview, but not informed of what factor limited or allowed their participation. The reason this was not disclosed was to prevent women from falsifying information in order to obtain the incentive. As previously mentioned, those who did not qualify were not sexually active at all, or had been with their current partners for more than five years. The questionnaires of women who were found eligible to participate were kept in a locked filing cabinet available only to the researcher; questionnaires of those ineligible were immediately shredded at Francis House. The questionnaires of

those eligible to participate provided basic background information of each participant including age, number of years since diagnosis, mental and emotional health statuses and mode of HIV transmission.

Semi-structured Interviews

Following the determination of eligibility to participate, interview date and time were picked according to a mutual agreement between researcher and participants. All nine interviews took place at Francis House, in a private office with the door closed. Interview questions served as guiding points for the discussion, but probes and follow up questions were used for clarification or for additional detail. Semi-structured interviews were utilized in order to gain rich detail into the lives of the women, allowing them space and time to describe, in their own words, how HIV has influenced their lives, sexually and otherwise.

All but two women allowed the interviews to be audio recorded, which were later transcribed verbatim by the researcher. Interviews lasted between 35 minutes and an hour and 45 minutes, the majority completed near one hour's time. Questions begin broadly, asking the participant to describe herself, how having HIV has impacted her life, and what her romantic and sexual life was like before diagnosis. Next, questions narrowed to focus on living with HIV, and how this may have affected partner selection, disclosure, condom use, and definitions of intimacy. Finally, the interview guide prompted a discussion of how drug and alcohol use and laws requiring HIV disclosure may impact their sexual decision-making. A copy of the interview guide is in Appendix B.

Data Analysis

Due to the small sample size of this study (n=9), reaching saturation with the data was unlikely. Thus, qualitative data analysis served to identify and explicate themes, highlighting what corresponded with existing literature and what diverged. Each interview was read in full at least three times, focusing on Ryan and Bernard's (2003) techniques for identifying themes including paying special attention to repeating topics and transitions to new topics initiated by the participant. Further, the constant comparative method served to highlight the idiosyncrasies that existed among all the participants (Ryan and Bernard 2003). Once common themes were identified, quotes relating to the theme were pulled from transcripts and sorted accordingly using Microsoft Excel and Microsoft Word ©. Quantitative data from the screening questionnaires were analyzed using SPSS Version 20 ©.

Chapter 4: Results

INTRODUCTION

This chapter will present the findings of the research conducted at Francis House. As suggested in Chapter 2, structural level factors disadvantage black Americans, and when coupled with unique circumstances, such as elevated rates of incarceration, stigma, and unbalanced sex ratios, these factors disproportionately increase the risk of HIV infection for African Americans as compared to other ethnic groups. As will be discussed in this chapter, many of these influences continue to weigh upon the lives of HIV positive individuals once they become infected. In addition to feeling the impact of these forms of structural violence, sero-positive women must learn to navigate disclosure, relationships, and safer sex. The results of the interviews discussed here lend support to the literature presented in Chapter 2. They also challenged existing post diagnosis literature and brought up various additional areas of interest.

Due to the small sample size of this study (n=9), any potential similarities or differences among participants are likely due to chance, and cannot be interpreted as generalizable to other black women with HIV or other populations. Despite this limitation, most women shared their viewpoints and experiences on areas of their lives, beyond sexuality, that were influenced or affected by their HIV diagnosis. Accordingly, this chapter will be structured around these resulting themes, providing vignettes of women whose narratives are particularly poignant or exemplary.

After presenting demographic data for the study sample, this chapter will highlight the themes that arose from the semi-structured interviews, beginning with macro-level influences, moving into how HIV affects interpersonal relationships, then finally to the most subjective encounters described by the participants.

DEMOGRAPHICS

The women in this sample (n=9) ranged between the ages of 37 and 53, with a mean age of 45 years. All reported contracting the virus via heterosexual sexual contact, which corroborates with national data that states 85 percent of black women are infected through sex with men (CDC 2011a). On average, eight years lapsed since diagnosis, with the newest infected two years prior to the interview; one participant has been living sixteen years with diagnosis, the longest time of all sampled participants. It must be noted though, that some women suspected they were HIV positive before their diagnosis; thus, it is possible that some have been living with the virus longer than their actual time since diagnosis. Figure 1 presents the age and number of years each participant has been living with HIV. In terms of education, two women were working towards earning their GEDs after having dropped out of high school many years before, four had a high school diploma or equivalent, two reported attending some college, and one woman held a Master's degree.

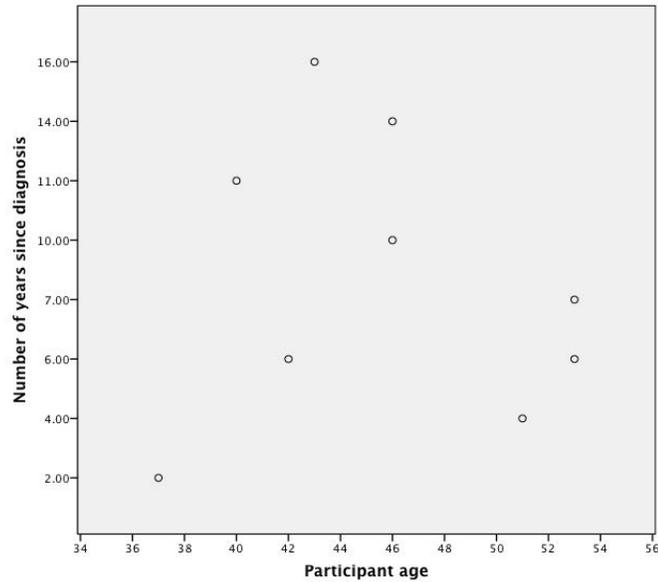


Figure 1. Participant age and number of years living with an HIV positive diagnosis.

The screening questionnaire collected self-reported health status information (see Appendix A). Five women reported their general health to be “good,” three “fair,” and one “very good.” Other questions gauged the number of self-reported days a participant experienced poor physical health within the past 30 days (Figure 2), the number of days a participant experienced poor mental health within the past 30 days (Figure 3), and the number of days a participant was unable to perform their usual activities in the previous 30 days due to poor physical or mental health (Figure 4). Participants were asked to answer using a number between zero and 30 days, and would occasionally expand on the reasons for their answers, but these data were not recorded.

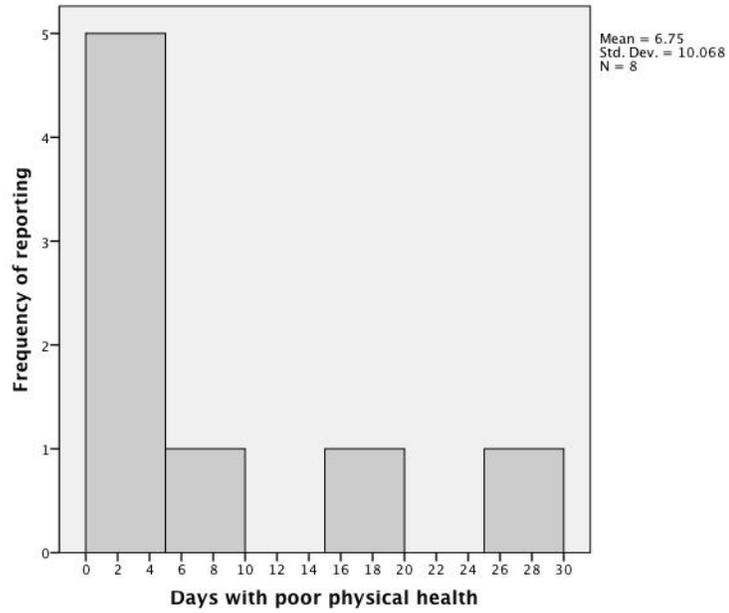


Figure 2. Reported number of days of poor physical health within the previous 30 days.

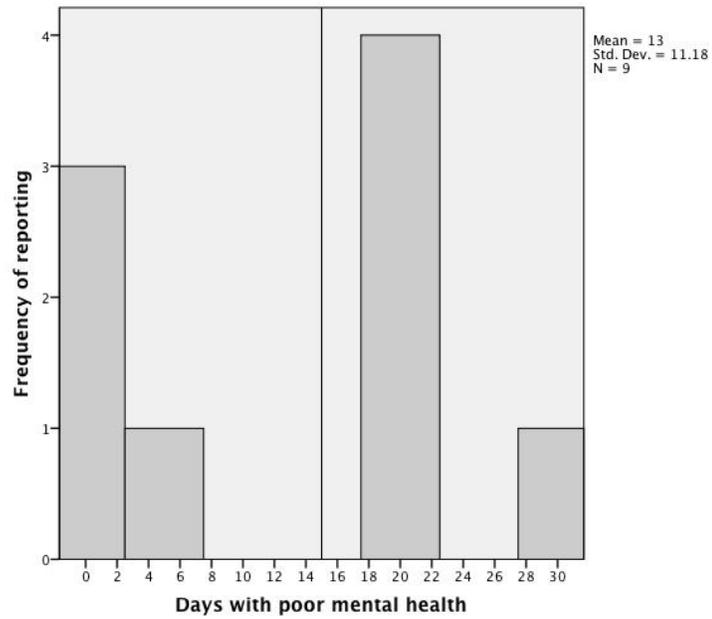


Figure 3. Reported number of days of poor mental health within the previous 30 days.

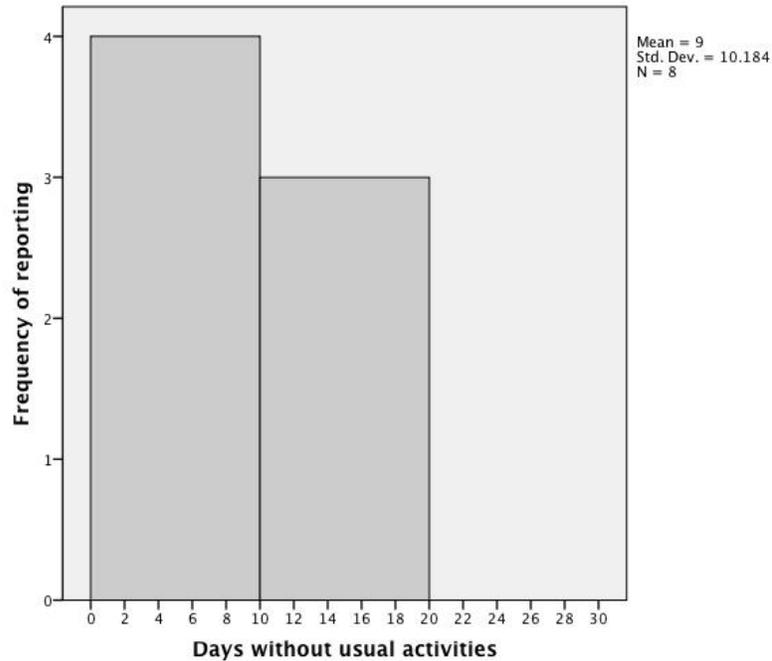


Figure 4. Reported number of days of poor mental or physical health that kept participant from completing their usual activities in the previous 30 days.

Figure 1 demonstrates that overall, between zero and six days of poor physical health was most frequently reported by participants (five total), with three participants reporting more--around eight, 18 and 28 days of poor physical health. As Figure 2 evidences, mental health was reported to disrupt a greater number of days for participants, with four women reporting around 20 days of poor mental health. Finally, Figure 3 shows that no participant reported more than 20 days where poor physical or mental health kept them from completing their usual tasks, instead three women said about half their month was disrupted, and four others reporting around one week of interrupted activity.

PREVALENT THEMES

This section presents the emergent themes of this study, with the bulk of data collected through semi-structured interviews. Some of the interview data collected are

supplemented with anecdotes or client commonalities encountered through participant observation. Within each theme, the participants that best illuminated the theme are described. Complementary quotes are provided to demonstrate the shared experiences of some women, as well as quotes and stories that contradict, demonstrating the variations in experiences within this group. It should be noted that all participant names used are pseudonyms.

The themes discussed in this section begin broadly, looking into the struggles created through structural violence, institutional racism, and early life difficulties in the lives of these women. Their diagnoses brought a great deal of stigma to the forefront of their daily existence, leading them to isolate and often suffer from dangerous mental health challenges. In terms of their sexuality, a variety of disclosure patterns are represented within this small sample. Condom use was also varied, with women expressing diverging reasons for their use or non-use. Four women in this sample have partners who are also HIV positive, an area that deserves special focus. Finally, this section concludes by looking into how HIV has impacted the sexual satisfaction and intimate moments among the participants.

Introduction

After just a few interviews, it became clear that it was difficult for the participants to compartmentalize their sexual and romantic lives from their everyday lives and relationships in general. Their HIV diagnosis appeared to influence multiple areas of their lives. And while much of this section will appear unrelated to sexuality, the breath of this discussion demonstrates how deeply HIV has permeated the lives of these women.

Life Struggles and Structural Violence

You know, because I remember my daughter asking me when I first found out [about being HIV positive] was I mad? Because I hear people talking about how they broke down and how they cried. I didn't have time to do that. I didn't have time to break down. I still had two people under the age of 18 that I had to get through school that I was responsible for. So I just did what I had to do as a parent, you know? I didn't let the HIV affect me. I took care of my kids, I did what I had to do. (Simone, 51, living with HIV for 4 years)

The stories I was privy to in the small office with olive walls were not always easy to hear. Structural violence was evident in the lives of the respondents, though none of the participants would have used that phrase; as Farmer (2005) states: “structural violence all too often defeats those who would describe it” (40). The lives of these women placed them at risk from the start simply by their social position which is shaped by “historically given (and often economically driven) processes and forces that conspire to constrain agency” (Farmer 2005:40).

The scenarios I present throughout this section are not intended to remove all personal agency from the participants, as it is often difficult to define the exact point where structural violence stops, and personal responsibility begins. Instead, their stories are useful for gaining an understanding of the many challenges they faced from the beginning of their lives—stressors that led them to places with consequences they regret deeply. Each of the nine women shared misfortune frequently reflected in the literature; three women have experienced rape, three have been incarcerated, two have had bouts of

homelessness, and two reported staying with men deep within drug addiction in order to maintain housing and some semblance of financial stability. Most shockingly, eight of the nine women reported being recovering drug addicts as well as previously engaging in sex for drugs or money. This section introduced Raquel, Crystal, Yvette, and Sasha, who all experienced their fair share of life circumstances that were out of control, but elevated their risk for HIV infection.

Raquel is a quiet, yet sincere 46 year old woman who spends her time at Francis House reading her bible or other books on Christianity and self-improvement, studying for the GED, or contemplatively sitting in solitude. She has been living with HIV for 10 years. Always careful with her words, Raquel's story clarified her seemingly self-preserving nature. Turning to drugs seems a natural choice after a tumultuous childhood that pushed her to face adult realities too quickly; her mother inflicted emotional and physical abuse through rigid, irrational rules, physical abuse, and an overbearing need for control, unapologetically dating men who sexually abused Raquel. Emotionless, Raquel remembered childhood with her mother: "Rules and beatings. Control. I could never ask her questions because I feared her. You had to be quiet all the time. Couldn't ask her anything about homework. I was called down on a private moment in my life, and I never asked her anything again." She remembers how her mother always put her to work cleaning the house for hours at a time. Once she stood up to her and told her she was not going to clean anymore: "My mom put a gun to my head. She cocked it and the gun didn't go off."

Her father's identity remains a mystery—she has never even seen a picture of him: "I never knew my dad. She [her mother] didn't tell me who my dad was. I couldn't

ask any questions about him.” Early into her childhood, Raquel began “lashing out” as a response to her circumstances. “I felt like a misfit,” she remembers, “I’m a runaway. I started running away when I could walk. At the age of five or six. I was rebellious at the age of five or six. As soon as I could use my head.”

The troubles did not end after childhood and escaping the tight grip of her mother’s domineering rule. Raquel has two children with two different fathers, and lost both of them. She states: “I didn’t raise any of my kids.” Because of the “situation[s]” she was in at the time, she “let them go.” The first child was taken by the father; Raquel felt it was better to get away from a dangerous relationship than it was to fight to keep her child. Raquel told a daunting story of how she lost the second child: “We [she and the father of her second child] would fight in the yard. He was pulling my baby’s arm and I was afraid my baby’s arm would break. I let him [the baby] go.”

Raquel’s story was so horrifying, it simply made sense that she would turn to drugs as an escape. She vividly recalls the moment her addiction started. “Hit this here,” said a roommate with whom she shared a rented house. She took her first hit from a crack pipe. “Then,” Raquel said, “the cravings started.” Chasing drugs meant trying to please the “boys” that came with them: “In order to have the boy you go out and do things to get money and stuff. All your good sense could tell you one thing, but your body another. Drugs put you in positions you wouldn’t have been in if you wasn’t on drugs.”

Drugs and desperate approval seeking meant chasing the man who knowingly infected her with HIV. Admittedly naïve, Raquel accompanied him to a doctor’s appointment at the health department where he handed her an intake form. “If you love

me, you'll fill out this paper," he said, fully aware that she was about to find out she was HIV positive, and that he had given it to her. He left to use the restroom and never returned. A doctor tested Raquel for HIV. She recalls, "Told me right there that same damn day. He explained to me what HIV was and I went into a zone." She ran to a nearby park where she knew her boyfriend would always hang out, frantically trying to find him, "I looked all over. He wasn't there. He deserted me. I was angry enough to fight." Yet, months later when he appeared, she met him with sympathy: "I couldn't hate him because I loved him."

Crystal is a statuesque woman of 43 years who has been living with the virus for 16 years. She expressed frustration with the constant struggles life throws at her: "I'm tired of taking responsibility." The hurdles in her life appeared early--she was raised by an abusive, alcoholic mother. She spoke of her life matter of factly:

By the time I got 19, early 20s, I started using drugs. Went to prison. After I got out of prison I didn't have nowhere to go. I started running the streets and tricking and stuff. Turned into AIDS. And I ended up going to St. Pete with this guy. He went to prison, so I went back to the streets because I didn't have a job.

Crystal was arrested twice more; the first time, she was sent to a drug treatment center in Bradenton, Florida. The second time, when she found herself without money and stole food to eat from a store, she returned to prison because when she was arrested she was carrying drug paraphernalia—a "crack pipe." She was given a third degree felony, too, when she was riding in a car with her cousin and did not realize the car had been stolen.

The way Crystal simultaneously spoke about her drug use and being HIV positive made her appear less than shocked that she became infected:

One of the guys I had started to date with had told me that he was HIV positive, he got AIDS. He got that shit. I was like, don't worry about that. Because with the crack, for me when I first started using it, I had no control. I had no control. I just—I just—I was just living each day to get high.

Once she got into a drug treatment program they offered her anonymous HIV testing: “I already told them I was positive. It was a shock to find out I was positive, but I always felt it.”

Interestingly, Crystal was the only participant to reference the HIV/AIDS epidemic in the black community. Her awareness had been recently raised from a documentary she watched. From the poverty, she said, that is why it is so prevalent. Referring to the troubles of women in particular, she makes reference to survival sex:

I mean, some women would [engage in transactional sex] that don't use drugs. They go out there and they turn dates and stuff for money to get things for their kids. I mean, I know this is a fact. They don't use drugs or anything. They just go out there and do whatever they have to do for their children. But then you got like 50 percent of us that are on drugs. It's hard getting a job.

Crystal is one of two women in this sample with a college education, yet the challenges of unemployment and underemployment have plagued her for years. She states:

It's hard getting a job. I imagine because I'm black. And then I can't say it's my education because I have a college degree. I just—and then I have a criminal background. I'm still trying to find a job because the disability check I get don't support me. I live—I have to live counting, wondering who's gonna like, buy me cigarettes or you know, if this person will help me, or that person will help me. Because my bills take everything I have. I live from check to check and I don't want to live like that. I'm 43.

As mentioned previously, two women were in a relationship with men for financial benefits, though they admittedly knew it was not the healthiest situation. Sasha, 42, and living with HIV for 6 years, has a boyfriend who is a crack addict who stays gone for

days or even a week at a time. As a recovering addict, she lives for her sobriety, children, and church, but refuses to “put out” her boyfriend because his disability check pays the rent; the food stamps and child support she receives are not enough to live on. Sasha knows her current boyfriend is having sex with other women during the time he disappears, so she protects herself through insisting upon condoms, a point that will be discussed later.

It seems this is just one of a number of bad boyfriends that have plagued Sasha. She was previously with two HIV positive men, neither of whom told her of his infection prior to having sex with her. One continues to deny his infection, and the other’s status was revealed by his lawyer in court. Sasha remembers the controlling nature of the latter boyfriend:

He was abusive to me. Jumped on me, making me stand on the corner with him while he sell drugs. And you know, like I said, I was living a hard life—rough life. He just took me from my kids and had me just with him. I couldn’t do nothing but be with him. You know, he beat me, jumped on me, do all that old crazy stuff. And one day we went to court and I hear the lawyer say that he was HIV. And I was like, did they say that? And he finally came out and told me.

Yvette, 46, and living with HIV for six years hesitantly described her tumultuous past: “I’m going to GED now, cause that’s an accomplishment that I want. I didn’t finish high school. I dropped out in the ninth grade. Um, because of family...dys—dysfunctional family issues.” In a previous conversation, Yvette revealed that she left home at 13 with her older sister, who taught her the ropes of living on the streets, such as how to “turn tricks” for money or drugs. Like Raquel, Crystal, and Sasha, a life of drugs, alcohol, running the streets and engaging in transactional sex was the norm for Yvette: “I was on drugs at the time, and on the alcohol real bad, and I was out on those streets. I

had a place to live, but I wanted my drugs and my alcohol and I didn't have a job. I had to go and get that money some kind of way and I sold my body.”

Raquel, Crystal, Yvette and Sasha's lives are only a few examples of past and current circumstances that place their health at risk, mental, physical and emotional. As their narratives show, their lives have been and will continue to be shaped by the societal limitations placed on them due to their social position, race and gender.

Stigma

People hurt your feelings about HIV. Regular people outcast you. They reject you. Say you diseased. Get it by the toilet and mistreat you if they know you have it. (Raquel, 46, living with HIV for 10 years)

Although it has been more than 30 years since the first public report of HIV/AIDS, stigma, misinformation, and discrimination against infected individuals continue to persist. This was witnessed repeatedly during interviews and periods of participant observation. Men and women alike told stories of friends and family who refused to share plates, cups, and utensils with them or who excessively cleaned toilets and tables after they were used by the HIV positive person, including Crystal who recalls when she was first diagnosed: “I used to sit back and listen. ‘Ooh, you shouldn't drink out of that cup you might have AIDS.’ ‘Don't eat none of that, they might have AIDS.’” Even Crystal's mother took excessive precautions: “If I came over with my son, I remember she used to take [rubbing] alcohol and put it in a bottle—little jar with balls of cotton. Wiping her hand every time she touch my baby.”

These previous quotes reflect a topic which clients of all races and genders brought up: the need for widespread education of the general public. Among the women

interviewed, stigma created a series of negative effects, including fear of disclosure, isolation from others, and a lack of social support, all of which will be presented in greater detail in the subsequent sections.

All but one participant mentioned feeling like the people around them lacked “education” about HIV, mainly their assumptions that it can be transmitted through casual, non-sexual contact such as hugging, kissing, or touching. Some, like Natasha, took action when they witnessed misinformation about the virus around them. Natasha’s seventh grade daughter came home talking about what she heard from a teacher in a discussion they had about HIV/AIDS. Knowing her mother’s HIV status, Natasha’s daughter had not seen in her mother what her teacher described. Natasha recalls her daughter may have sensed it being incorrect: “So I went to the school and I told the principal that she’s not giving correct information.”

Sasha, too, tries to dispel myths when she hears her children talking about HIV. She has not informed them of her HIV status. She stated:

Well they got friends and they hear rumors about other people. They be like, ‘Oh she got AIDS or something.’ Then I be telling, ‘Ya’ll need to stop talking about people. Ya’ll don’t even know what you talking about.’ You know I’m gonna defend it because you can’t get it like this, you can’t do that and get it like that. They just children. Even though they young teenagers, I just try to keep them on the condoms.

Additionally, participants reported feeling like people are “negative” about the virus, and often feel they have to “bite [their] tongue” to avoid lashing out in frustration, which might make others suspicious about their infection. The memory of Ryan White, a widely-televised young man infected with the virus from a blood treatment for his hemophilia in the early 1980s, was occasionally brought up by Francis House clients. White served as an example of the horrific discrimination suffered by people with HIV.

Sadly, the stories heard over the course of this research did little to show that stigma has diminished since the days of Ryan White.

During both participant observation and interviews, Francis House clients made reference to the notion that ultimately they feel HIV will not be their cause of death; life-extending antiretroviral therapy instilled confidence that they could live as long as anyone else. Crystal emotionally reiterated this argument: “People are so ignorant. They say bad things about people with the virus. It’s like we’re aliens. Like we’re aliens or something. We’re humans just like they are. What about a person that has cancer? They don’t discriminate against them.” She continues, “If I could just change it, I would, but I can’t. It’s hard. It’s hard living with the virus. It’s really hard. Cause some people are so ignorant to the fact that the virus is just like cancer. You may die faster from cancer or diabetes than you will from the virus.” In terms of dying from HIV/AIDS, some women mentioned their fears of immediate death or a shortened life due to their infection, but all had a more hopeful outlook once they spent more time in the HIV community and understood the benefits of antiretroviral medications. Yvette was reminded that others still see AIDS as a death sentence, and was frustrated by their unwillingness to differentiate between HIV and AIDS:

Because a lot of people think they know what they’re talking about and they don’t. They think they know what HIV is, and a lot of them don’t say HIV, they just say AIDS, instead of saying HIV is the disease that causes AIDS. They’re thinking they can catch AIDS and they can die. That it’s a death sentence, that’s what they’re thinking.

This lack of consideration was hurtful for Yvette: “A lot people don’t care what they say to you, and this is that kind of society today. They don’t care whether they’re hurting you or whatever.”

Michelle, a 54-year-old woman living for seven years since her diagnosis, relies on religion and her church for a sense of peace and support, like most of the women interviewed. Surprisingly, she was not the first woman who shared a story of a preacher who advised her against telling anyone else at the church of her HIV status:

Michelle: Getting involved with the church family and this [Francis House] family helped me more with my HIV. Last time I went to another church I had told the preacher about it [her HIV infection], so the preacher told me don't tell people that I had it, which is good. So I'm at another church now with a new family. I'm not gonna let people know I have HIV, no. Pray for healing for my body—you ain't gotta know what's wrong with it.

Interviewer: What do you think their reaction would be if you told them?

Michelle: If they knows it, they knows it, they knows it. Certain type of your business you gotta keep to yourself because they'll go talking amongst theyself because they human too. So they busybody too. So, best thing to do is keep about your business. Take care of yourself, your own self.

Examples such as this demonstrate the disheartening truth about the role of black churches and the HIV epidemic. Michelle's description of the preacher encouraging her to keep her HIV status a secret as "good" is particularly interesting, and may indicate her devotion to her faith despite her church's reluctance to acknowledge the damaging effects of HIV/AIDS among its members and greater community. She did not appear surprised or bothered by her preacher's request, instead she appears to feel it justified her desire to keep her status a secret for fear that others would talk behind her back or tell others she is HIV positive.

As alluded to earlier, stigma was a topic present not only in interviews, but also commonly discussed during support groups and within many of the personal conversations with Francis House clients. Undoubtedly, stigma is a contributor to

depression, anxiety, and other mental health problems and to the tendency to isolate oneself, which are discussed in the upcoming section.

Isolation and Mental Health

It feels—it makes you feel dirty. It makes you feel nasty. It just makes you not want to be around anyone. I'm talking about anyone. It makes you wanna isolate yourself (Yvette, 46, living with HIV for 6 years)

As previously mentioned, the highly stigmatized nature of HIV leads many of the women to isolate themselves from others and suffer from mental health troubles including depression, stints in mental hospitals, and suicide attempts. Also, it appears that some women self-medicated after their diagnosis through the use of drugs or alcohol. Not surprisingly, the four women introduced in the section addressing structural violence and life struggles, Raquel, Crystal, Sasha, and Yvette, also revealed examples of how their experiences have proven detrimental to their mental health.

Raquel's first suicide attempt occurred after her second of two children was taken from her due to her addiction. "I felt so filthy, dirty, hopeless," she stated. Suicide became the most obvious solution to her problems "three or four times." Overdosing on pills once put her in a coma. A bout with pneumonia whittled her small frame down to 89 pounds and she was simply sent home to die by the doctors. Yet, somehow, it was the same mother who held a gun to her head as a child that came to save her when Raquel gave up on life. "She came in and got me [from the shower where she was attempting suicide]," Raquel describes, "She said, 'I love you. Stay strong.' She pulled me out and wrapped me up and took me to my room. Laid there with me for a while."

Today Raquel does her best to stay focused in order to avoid the pit of depression, suicide, and the voices that “fester” in her mind; “If I don’t stay in a book that’s positive, a stepping stone, then I’ll lose it. It don’t take but one blink of an eye and I’ll be back on a boat I don’t know how to sail.” Her life story was punctuated by quoted scripture, a testament to her reliance on her faith to provide comfort and security: “You hear me talk about the Lord. I have nothing else. My life has been nothing but chaos. My life has been nothing but chaos. My life has been nothing but chaos.”

Like Raquel, Sasha, too, has attempted suicide. After proudly announcing her T-cell count as 364 and boasting about an undetectable viral load at the beginning of the interview, Sasha nostalgically recalls her previous lifestyle as a socialite: “I was a pretty popular girl out there. You know, clubbing and dressing, and jewelry and all that.” All night parties took place at her house after everyone left the club, mostly because she sold marijuana and cocaine. But her diagnosis with HIV “changed everything.” From there, her fast-paced partying life “completely slowed down.” She recalls the whispers of others who noticed as she shied away from men who approached her: “They be like, damn, she always pushing somebody away. She always—she’s so mean. She’s so this. It ain’t like that. I know my status. And I ain’t trying to spread it. You know what I’m saying?”

Sasha dealt with her diagnosis by seeking out an HIV positive mate, but as discussed, his crack cocaine use brought up a host of other issues. She is currently sober, but the legal repercussions of her past continue to follow her. She is on one year of probation and must complete 50 community service hours for selling powder cocaine and marijuana. More about the experiences of Sasha will follow.

Crystal, now clean from drugs and alcohol, still lives in poverty, attempting to remain patient while she waits for housing assistance to allow her a better place to live. Her monthly disability check of \$698 spends quickly when rent for her deteriorating apartment is \$470 per month. Crystal is behind more than 130 people in the waiting list for Housing Opportunities for Persons with AIDS (HOPWA), a federally funded housing assistance program, and is near number 600 for the Tampa Housing Authority waiting list. As she states, at times the situation is just too much for her: “Sometimes I just sit on the bed and cry. My boyfriend coming in saying ‘What’s wrong? Who’s messing with you? Who did something to you?’ I’m like, ‘Nobody,’ I said, ‘I’m just tired of living like this.’” She wonders if she will be able to afford Christmas presents for her son, especially considering she was unable to give him a gift for his birthday.

Crystal mentions her difficulties sleeping due to her depression and anxiety: “I’m up all night thinking how am I gonna do this? I got all my stuff packed up in my room, can’t even move around. How am I gonna move all this stuff? I don’t have a truck, I don’t have a car. I don’t have no money to pay for a U-Haul.” She previously had taken Seroquel, an anti-depressant, which she hopes to get back on in the near future: “I feel that if I get back on my medicine it will really help me sleep at night. Right now it’s just—it’s just, just a merry go round, everything. How am I gonna do this? What am I gonna do about that? You know, I’m thinking like way ahead.”

In addition to her faith, Yvette uses counseling to address her painful childhood, but admits it has not been an easy process for her: “When I first started counseling I was depressed. Very depressed. And it was dramatic, my first meeting. I cried a lot. Sometimes I still cry. And I don’t know why, sometimes I cry and don’t know why I cry.

But hey, it's better out than in. I see it that way.” In addition to depression, Yvette states that she is often lonely, mainly due to her hesitation to get too close to other people because of her HIV infection: “Yeah, that's what it does. It makes you wanna isolate yourself. You go into a depression mode. All kinda thoughts go through your head.” She tries to keep herself busy to counteract the loneliness she feels is inherent to living alone: “I deal with it. Sometimes I get very lonely, but I go to church, I read my bible every day. I get into a movie, and I'm good. I get to cleaning my house and I'm ok.”

Mental health complications with HIV positive individuals, especially black women, are well documented (Catz et al. 2002; Lichtenstein et al. 2002; Vyavaharkar et al. 2011). This section's discussion aligns with these findings, and demonstrates that mental health troubles are a theme throughout a variety of stages of the life of someone living with HIV/AIDS. As the next section will reveal, the threat of rejection as a potential outcome of disclosure also looms in the minds of many of these women.

Disclosure

For years, nobody knew. I didn't tell nobody. (Simone, 51, living with HIV for 4 years)

In response to the stigma faced by the women interviewed, it is easy to understand their tendency to isolate themselves. Accordingly, the decision to disclose one's HIV status to others is convoluted. Various methods of disclosure are utilized according to who is being told, the nature of the relationship with that person, and the potential consequences or benefits that may arise from the disclosure (Serovich et al. 2005; Sowell et al. 2003). This section will discuss the various methods of disclosure and the circumstances under which they take place. First, disclosure in general, to friends, family,

acquaintances and even strangers will be discussed, followed by disclosure in the context of romantic and sexual relations.

In general, the women were very secretive about their status. As the quote at the beginning of this section demonstrates, fear prevented participants from telling anyone around them of their status, especially soon after their diagnosis. Crystal recalls: “When I got diagnosed I wouldn’t tell nobody and I don’t go to doctors. I guess it was ’96 when I got my diagnosis. I would sign in at the health department but I never go to appointments. I never take the medicine. I was, like, really shamed.” Furthermore, the risk of violence that may accompany disclosure was a real threat to some women, who alluded to stories of women they had known to face such fate. Raquel stated succinctly: “You can’t tell nobody nothing because they’ll kill you on the street.”

In terms of learning how to ease their fears and develop the courage to disclose their status to others, Simone, Sasha and Michelle mentioned the comfort they found in attending Francis House support groups, and felt especially grateful for the understanding and non-judgmental attitudes of staff and clients. And while their safety was guaranteed within the walls of the facility, Michelle felt better disguising her attendance to Francis House support groups, or what she called “classes,” from outsiders saying:

Cause when anybody see me and they see me on the bus, “Michelle, where you been?” “Oh, I been to my classes.” And I’m not lying! And my class—“What kind of class?” “Oh, this class where you have to have a certain type of health to go there.” I cut it off like that. I don’t have to tell them anymore. That’s the end of that.

Surprisingly, the fear of disclosure prevented four of the nine participants from revealing their HIV status to their own children. Jasmine, the most recently (two years prior) diagnosed of the participants is waiting for her son to get

through college before she tells him her secret: “I don’t wanna worry him. I want him to finish his education, and then I’ll talk to him.” Her HIV doctor suggested she wait to disclose to others because she is not on medication, and has blood work indicating she is in good health. She recalls talking to her case manager, too, about when the right time might be to disclose to her son: “I get a little bit emotional when it comes down to that. Gonna be kind of hard to tell him, but it’s not time yet.”

Crystal, too, wept, overwhelmed, as she spoke of her youngest son, wondering if she should let him know about her HIV status. She asks: “I’m helpless right now. Should I tell him? Will he look at me any different? Maybe he won’t come back [to visit].”

Both Michelle and Sasha have not personally told their children, but feel as if their kids are likely to know already. For Michelle, drugs and multiple arrests hindered her ability to raise her children on her own, so they live with her sister. Michelle feels confident her sister has already told her children about her status. Sasha feels her children discovered the pamphlets she recently took home from Francis House, when she went home and found they were not as well disguised as she had originally left them.

The reality that four women within this sample have lost custody of one or more of their children due to involvement with drugs and the correctional system may make the threat of rejection from a child even more substantial. Unlike Michelle, Crystal, and Raquel who lost custody of their children but are still in contact with them, Faith recently began an effort to reunite with her 16 year old

daughter, with whom she has not been able to speak and has not seen since her daughter was five. After spending five years incarcerated, Faith now focuses her life on sobriety from crack cocaine, developing her faith in God, and finding a way to reintegrate her children into her life again.

Those who were hesitant to live openly with their HIV status due to the potential for rejection and judgment often appeared equally afraid of what is called “second-hand disclosure,” or having one’s HIV status revealed by another person (Serovich et al. 2012). Natasha, 47, and living with HIV for 14 years, had her HIV status exposed in this manner; her mother knew of her status, but not her sister. Unfortunately, while the three of them were having a conversation, her mother exposed her status to her sister:

We were talking one day and she says something about Metro Charities [a local AIDS service organization in Tampa] and I looked at her and was like, “Be quiet, you know? Why, you know, why you saying [that]?” And then she looked at me and it was like nothing. It’s like, how could you have said something like—how could that happen and you not tell your sister?

Crystal also experienced this type of second-hand disclosure, as when she went to reveal her HIV status to her current boyfriend, he told her he already knew—Crystal’s brother had told him. For Michelle, too, second-hand disclosure was a reason to maintain the privacy of her status to all people: “When you tell them, your secret is out there. And once you break up with them, your secrets out there. They can make you look bad. Because once your secrets out there, and they telling, everybody gonna know your business.” Interestingly, a second-hand disclosure prompted both Natasha and Jasmine to discover their being HIV positive, as mutual friends encouraged them to be tested due to their sexual involvement with someone known to be infected.

For romantic and sexual disclosure, the four common methods of disclosure discovered by Serovich and colleagues (2005) will be discussed: 1) *Point Blank*: the most direct of disclosure types where one simply states “I have HIV.” This is also said to carry the most risk; 2) *Stage setting*: this type of indirect disclosure provides hints or clues to the individual the infected person is attempting to tell. It allows the infected individual to gauge someone’s openness to or attitude about HIV, or to provoke a discussion of HIV; 3) *Buffering*: this utilizes an additional person or strategic location or event to bring up HIV or to fully reveal one’s HIV status to another; and 4) *Seeking Similar*s: strategically spending time at or attending events in a setting where those participating will be HIV positive or will not object to others being HIV positive. Additionally, Black and Miles (2002) posit women utilize a “calculus of disclosure” to determine “what is at stake,” and whether or not to disclose their status (691). This concept revealed itself throughout the interviews conducted, although no definitive patterns emerged; thus, only examples of the “calculations” that may be involved (Black and Miles 2002:691) will be presented here.

Yvette, 46 and living with HIV for six years, is a former crack addict who left home as soon as she dropped out of high school in ninth grade. As a point blank discloser, Yvette is aware that disclosure is a high stakes game:

It’s hard to disclose to the opposite sex because you know, you got to be strong when that happens because you got to let yourself know that he might reject you. He might walk away. But you have to say to yourself, if he does, he does, if he don’t he don’t. I’m glad if he don’t, but if he walks away then I’m ok with that. Because you can’t expect people to understand where you’re coming from and what you have, what you’re living with.

One way Yvette calculates the risks that disclosure may pose is to determine how her HIV status may affect another person, if at all: “I don’t just disclose to everybody. What people don’t know won’t hurt them, and sometimes it will. You know, you have to be honest about that. Sometimes it will, sometimes it won’t.” Yvette felt her HIV status mattered to a Hispanic man she briefly dated a few months prior to the interview. When Yvette could tell their time on the couch was progressing past just kissing, she knew she had to tell him her status. She recalls: “He said, ‘What? What’d you say?’ ‘I said, I have HIV.’ ‘For real?’ I said, ‘Yeah, so you gotta use a condom.’” Though they had sex that afternoon, his reluctance to kiss her during their next visit led her to believe someone had told him the virus was transmissible that way. In an effort to address his misunderstanding, Yvette, certified as a HIV testing counselor, pulled out her training guide to convince him of his safety. Despite her attempt, it did not take long before he stopped contacting her. She describes how she felt: “It didn’t bother me—maybe a little—I’m not gonna lie to myself, maybe a little. But it’s ok. I know I need to let you go. That’s what I thought to myself. You not for me. If you seen the evidence that says no, you can’t, and then you still skeptical, I don’t need that.” At the time of the interview, Yvette had begun dating a new man, but was waiting until things “get serious” in order to tell him.

Natasha, too, brought up the idea that once the relationship reaches a certain level of seriousness, disclosure was imminent. With her fiancé, Natasha was hesitant to disclose due to the fear that he would leave her: “I didn’t want it over. Keep this good feeling and enjoyment and excitement.” She kept “putting it off,” she said, even though she told herself, “You know, if you’re gonna have a future with him, you’re gonna have

to tell him. You're gonna have to face the fact whether he wants to deal with it or not. You gotta do it and get it over with. Cry, and whatever, and pray to God let these tears stop real soon. I gotta do it." Natasha's attempts to be a point blank discloser were sidelined by her boyfriend, who sensing her distress repeatedly told her: "If it's gonna make you cry, don't tell me." Eventually, she decided she had to tell him, but over the phone; if she were to do it in person, she said, he would be there to hold her, and she might lose her courage. He picked up the phone to only hear three words: "I have HIV." Then, Natasha hung up the phone. By hanging up the phone, Natasha protected herself, realizing that if he called back, it was likely to explain that he accepted her having HIV. Relieved, he did call her back, letting her know that it was not a problem—his cousin also had HIV.

When the person being disclosed to knows someone else who is infected, it seems to improve the likelihood of acceptance. Like Natasha, Faith, 40 and living with HIV for 11 years, found that her disclosure situation turned out positively due to her boyfriend's familiarity with the infection—his brother had died from HIV, and he has friends with it. Employing the stage setting technique called "symbolic hinting," Faith's HIV medications served as a mechanism of disclosure (Serovich et al. 2005). She recalls feeling like it was getting to be time to disclose to the man she was seeing, as their "whirlwind romance" was progressing towards a "sexual interlude." Sitting on a park bench, he came right out and asked her if she was HIV positive, as he had seen her medications sitting on her desk at home. His asking prompted a discussion on health—how they could both stay healthy through the use of condoms. The ease of this transaction was a "load off [her] shoulders," though Faith claims she did not purposefully

facilitate this scenario by leaving her medications in plain view. Justifying herself, she stated: “My meds are in a dispenser so when it’s time to take my meds, I’m fixing to take them. I’m not shooting up IV drugs so it doesn’t bother me what they think.”

Four participants have partners who are also HIV positive. Of the four women who are in sero-concordant relationships, three were able to bypass disclosure due to their having met through at a location that identifies them as HIV positive, in these cases Francis House (Michelle and Simone) or at the AIDS clinic at the health department (Sasha). Jasmine, a point blank discloser, happened upon her HIV positive boyfriend at a local hang-out. The stories of women in sero-concordant relationships are presented in the next section.

Sero-concordant Partners

I’ll find someone that’s HIV positive, that’s the same as I am. (Jasmine, 37, living with HIV for 2 years)

Four women, Michelle, Simone, Jasmine, and Sasha, are all in relationships with men who are also HIV positive. The latter three women could be described as “seeking similars,” or making a conscious effort for a mate of the same serostatus, while Michelle adamantly denies any desire to be with someone similar (Serovich et al. 2005). In fact, when she met her current boyfriend, she was focusing on sobriety and celibacy, what she felt God was telling her was right at the time. Michelle was drawn to her boyfriend because he “didn’t look like he had it” and appeared to “take care of his body,” two things that were important to her. Their desire to maintain good health appears to be a shared connection and source of comfort and security.

For Simone and Jasmine, being with someone positive provides benefits that would not come with a sero-discordant relationship. Simone states: “It’s easier, less complicated. I don’t even think I would get into a relationship with somebody that wasn’t [HIV positive].” Jasmine decided to be with someone “the same as [she] is” when she was diagnosed; they can “relate to each other” and she does not have to worry about transmitting the virus to him.

Based upon the dramatic decline in her social life and the subsequent depression and isolation that followed her diagnosis, Sasha’s reason for being with a positive partner appear to be rooted in a resolution that her life is forever changed because of HIV: “I try to stay within my boundaries, meaning, if I dated anyone, the person gotta be just like me. I know that may sound crazy, but I feel more comfortable.” This comfort is part of the reason why she does not “put out” her current boyfriend despite his crack binges: “I don’t feel like starting over again with nobody else.” Admitting his drug use is potentially detrimental to her sobriety effort, she is insistent that he will not negatively influence her: “That don’t mean I’m fixing to mess up, and start living my life again, no. Because I know now I can live. I’m HIV positive, I’m gonna live!” Interestingly, Sasha recently became sexually involved with a man she met at a bar and had been spending time with for the previous two months. After a successful point blank disclosure, which opened a dialogue for condom use, Sasha expressed excitement over not having to limit herself to only sero-positive partners in the future:

It feels good, it’s happy, it’s a good feeling. Let me know that I still got like, a chance, with somebody normal, you know? I ain’t gotta keep putting up with his crap and I ain’t gotta settle for just somebody in my speed, you know? Cause that’s what the condoms for. I can have a normal relationship and a normal life now.

Additionally, the successful disclosure also boosted her self-efficacy: “Cause I feel like if I could tell him, a perfect stranger, then I could probably tell my family, sooner or later. Not soon, but later.” As mentioned earlier, Sasha is one of the women who is scared to disclose to her on children.

Partner Selection

If I'm getting in a relationship today, it's got to be long term. Or for good because I'm not a person that's—that wants to just have sex and then you go your way and I go my way. I'm not like that. Because I been through too much. I been on them streets too long, and I'm not gonna live my life like that anymore because that's how I've lived my life all my life. So I'm not living my life in that term anymore. (Yvette, 46, living with HIV for 6 years)

A striking theme emerged in terms of the desire of the respondents to move away from casual sexual relationships and invest their time in more serious, long-term relationships. It seems the stigma, disclosure, and the potential for negative outcomes that may result push women away from traditional dating (i.e., courting multiple individuals) towards more settled, secure, and emotionally safe relationships; this seems especially true for the women who led “faster” lifestyles on the streets, as evidenced in the opening quote above. Faith echoes this sentiment:

It relaxes me to know that I got somebody that loves me for me. You know what I'm saying? Not [I] got to have sex with him because he got money or something. That's like back in the younger days. Yeah, sex had to be for the money. But now, our sex is without money, just because we feel like touching each other.

The theme of “getting to know each other” arose as the best part of current relationships for Yvette, Faith, Michelle, and Simone. Spending time together, seeing movies, watching television, and giving massages signified a worthwhile man and lasting relationship activities for these women, who shied away from men who too quickly insinuated an interest in sexual activity. Yvette stated: “When a guy is talking to me or something like that, they go talking like they wanna have sex and that’s all on they mind, I cut it off right there. No. I have guys asking me for my number and stuff like that, but I’m just not into guys like that anymore.” Natasha, too, found these advances undesirable: “I hate to meet a man that, ‘Oh, when are we gonna go to bed? You know? Or make love’ And it’s like, how can you make love to me and you don’t even know me?” For Natasha, a man who would stay with her despite her HIV status meant he really loved her, after all, “he could be with someone who doesn’t have this.”

Most extremely, Crystal, Raquel, and Natasha all suggested the difficulties entailed in living with an HIV infections may lead them to eventually give up on relationships or the opposite sex altogether. “I don’t think if me and my boyfriend break up I’d ever have another partner. I’m content living by myself. I don’t know. Just call it ‘old age syndrome’ or whatever. Look at the TV or listen at the radio. I’m content with that,” Crystal stated. Raquel, currently unsure of what the future holds with her fiancé agrees: “[I] don’t want to explain nothing to nobody else. Explain nothing to nobody. Be single. I don’t want to be rejected. I don’t want to be out there in the world again.” HIV makes things more “challenging,” she says “knowing the fact that you will have to disclose makes you less apt to go out and meet someone.” Her solution: “instead of facing that, just be alone.”

Condom Use

And he's like, all right, I'll use a condom. And then the next time we did, he didn't use one. (Crystal, 43, living with HIV for 16 years)

Overall, the interviews suggested condoms are used inconsistently, at best, for most of the women in the sample. A variety of reasons for the use or non-use of condoms was presented in both past and present sexual encounters. No one stated they had engaged in protected sex 100 percent of the time following their diagnosis. Many admitted to current and past sexual acts where condoms were not utilized.

In terms of protection from sexually transmitted infections (STIs), only one participant, Sasha, discussed the use of condoms specifically for this purpose.

Continually referring to the bowl of condoms on her dining room table, Sasha appears adamant and vocal about condom use for herself and her five children: "I don't need no extra trichinosis, I don't need no herpes, I don't need no syphilis, I don't need no crabs, I don't need none of that, what they got going on!" It must be noted though, that Sasha is the only participant who had both an outside partner *and* was confident her boyfriend was having sex outside of their relationship.

Among sero-concordant partners, the use of condoms is still suggested by health professionals. Individuals carry different strains of the virus, making those engaging in unprotected sex susceptible to reinfection with an alternative strain, which can lead to medication resistance or lessened effectiveness (Kalichman et al. 2010). Interestingly, among the participants, the desire to avoid potential problems with medication resistance became a more motivating reason to use condoms with a partner than the need to protect themselves against STIs. Michelle stated: "They say when two people have it, and they

have sex, that one of them could turn them to their medicine become resistant. And they have to get another set of medicines and stuff like that. So we all know about that.”

Simone, too, wanted to avoid becoming resistant to her medications because she wanted to see her grandchildren grow up, so she demands her boyfriend wear condoms despite his reluctance: “Well for my protection and his protection—because if his strain is different from mine or my strain is different from his.”

Despite understanding the need for condoms and the potential consequences of engaging in sex without them, some women admitted they wished they could sometimes go without protection. Crystal stated: “It’s just, you know, sometimes I feel like scrap up and putting on a condom. It’s like sometimes you think about, you know, if I didn’t have the virus we wouldn’t have to do that. You know, guys be like putting on a condom and like be struggling, he can’t get it on. It’s just sometimes, you just—it just kinda throw you off course.” Yvette expressed frustration as well, but stated she is “used to it now. I’m used to the changes that I had to make in my life as far as that goes, the medications, you know? Doing the right things to keep myself healthy.”

Jasmine stood out in this group of women as the only participant who openly admitted to not using condoms with her current partner. Because they are both HIV positive, have “the same strains,” are “faithful to each other,” and because neither she nor her boyfriend are on antiretroviral treatment, Jasmine is concerned about neither HIV reinfection nor STIs. Jasmine felt she was able to keep an eye on her boyfriend because he was living in a halfway house with strict rules, and therefore was unconcerned about the potential for him to be unfaithful. Jasmine had been previously “Baker Acted” for attempting to murder the man who gave her HIV on the day she was diagnosed, meaning

she was involuntarily admitted for a psychiatric exam due to her being a danger to others (Florida Statute 2012b). Thus, it was not hard to believe her when she said she would be in jail for attacking her current boyfriend if he were to cheat on her and expose her to STIs: “I’d be in Faulkenburg Road down there! I don’t roll like that! I’m faithful.”

Crystal and Natasha share a common experience with their boyfriends who express fatalistic attitudes about becoming infected by them. Crystal recalls her boyfriend saying, “He always tell me, like when he kiss me and stuff, he said, ‘If it was meant for me to get it, I’m gonna get it. But if it’s not, it’s not.’” She made it clear she was in charge of the decision to use condoms with him, reasoning that she did not want both of them being sick: “If I get sick you be helping me, but if you get sick, you can’t have us both sick.” Natasha says she has to “put [her] foot down” in the condom debate, but, like Crystal, struggles with having to take full responsibility for preventing her partner’s infection. Frustrated by being the one to always be concerned with condoms, she states: “You’re still a man and you’re out there too. It’s a free country.” At the same time, though, Natasha struggled to find a middle ground between protecting her boyfriend and pleasing him, recalling when she told him: “You never wore condoms with your wives. So you weren’t used to wearing condoms. So I want you to be as pleased as possible.” In the past, Crystal had difficulty with the burden of being accountable for condom use fully on her as well: “Somebody gave it to you, who gives a shit? I was saying in my mind—one side would say well who gives a shit? And the other would say well don’t, don’t spread it. Just because somebody gave it to you don’t mean you have to do it to them. I just didn’t care.”

Florida's HIV disclosure law subjects HIV positive individuals to a third degree felony (first degree if multiple offenses) if they fail to disclose their HIV status to a sexual partner, even if condoms are used or the virus is not actually transmitted to the partner (Florida State Legislature 2012a). Based upon participant observation, knowledge of the law was widespread amongst Francis House clients, and did appear to be a motivation to disclose to others. During interviews, participants expressed competing views on the usefulness of the law. Some showed a sense of fear for its potential consequences, fearing they would "go to jail" for "attempted murder." Jasmine, having actually attempted to murder the man who infected her, feels the law is beneficial because he is currently serving time for having failing to disclose to her. Crystal said she did not worry about this law until she knew a woman who suffered the penalties by spending time in jail. Most extremely, Natasha thought this law was "a bunch of crap" because after multiple attempts to press charges against the man who failed to disclose to her and subsequently infected her, she was disappointed when "nothing happened." Evidently confidentiality laws at the AIDS service organization he attended prevented verification of his serostatus.

Three women were willing to admit to times they failed to disclose their status to past partners and ensured condoms were used for safety. Instead of disclosure, Yvette says there are "different ways you can say it and not disclose." Though she would rather disclose, the prospect of the man walking away pushes her to rectify the situation by suggesting she and her partner "practice safe sex." Following her diagnosis, Raquel continued having sex with men she had already been with "in order to not give it to anyone else," using condoms when she could, "although that wasn't always possible."

Luckily, she “never had nobody come back.” Knowing what she did was not right, she remembers: “being on drugs, I still had to get money.”

Sexual Satisfaction and Embodied Experiences

She knows she has the disease. She could kill him. It could tear up her relationship. How can you lay under someone with those thoughts in your head? (Raquel, 46, living with HIV for 10 years)

Like condom use, the level of sexual satisfaction following diagnosis with HIV appeared inconsistent among the women. It appears sex and enjoyment were influenced by all of the issues presented in the previous sections—drug use and what it meant for their previous sexual encounters, the need to disclose, knowing they should be using condoms to prevent further transmission, the HIV status of their partner, and the nature and intensity of the relationship.

Michelle says one of the reasons she had to “cut sex out” during the period of her life immediately following her diagnosis was due to the difficulties of removing her infection from the bedroom: “It’s, like, it’s in my head. Even though we using a rubber, it just didn’t feel right.” Sasha struggled too: “It’s always here in my head, the back of my head, the front of my head, it’s [on] my mind.” Yvette says she still thinks about HIV “a little” during sex, but is more worried about her partner’s reaction, stating: “I hope he don’t freak out, you know, while we having sex. Thoughts gonna come into his mind, and he go to freaking out on me. But for me, it’s—it don’t bother me, as long as I’m protected and I’m protected them, I’m good.”

Similarly, Raquel found it took more time than she anticipated for her boyfriend to fully understand that she was infected with HIV, describing the multiple attempts to

disclose. Knowing this, she reflected, “How could you lay up under someone with those thoughts in your head? For me, it was rubbers. Release myself from the burden.” Like Raquel, Faith also found relief in disclosure: [It was a] load off my shoulders. I can pop my collar on that one. I was gonna tell him very soon before we got into a sexual interlude. I didn’t want to have that on my conscience that I slept with someone and wasn’t being totally honest.” This too, allowed for Faith to be less inhibited during sex with her partner: “Sometimes it will be especially fun when your partner knows. You can be more adventurous. Tongue kissing, touching. Because you can’t be like that with everyone. It makes me feel good. Makes me feel free. It’s something new to me and I’m enjoying every minute of it.”

A stark difference from the past, Michelle shared that she enjoys her sex life more now that she has HIV, due to the emotional closeness she has with her current partner: “I like to be up under him watching TV and stuff. Wake up in the morning, cook him breakfast. Get some then *and* get some at night time!” The addition of love increased Natasha’s satisfaction with sex as well:

How he feels about you has a lot to do with how you feel. You let yourself go and you don’t care about the roll here, and you know, and he accepts you and he don’t care. You know you got a fat butt, so what? He loves it. You know, and it’s, it’s great.

Not all women shared the same sentiment though, with some feeling their sexual drive, satisfaction, and enjoyment had lessened due to their sero-positivity. Yvette says she struggles to reach orgasm due to both her medication and the “HIV itself.” She shared that her sister, also HIV positive, struggles with the same problem. Similarly, Sasha stated, “I’m not as horny as I used to be,” blaming her aging body that “ain’t working like that no more.” Her past sexual experiences arose as well: “I done sexed myself. I’m

tired. And I do it when I feel like it. When I get an urge. If I don't get urge, it don't happen." This topic quickly led to a type of self blame: "Getting older, waking up, growing up and realizing I should have been thinking like this a long time ago. Or I wouldn't be in this situation. Well, I mean, lesson learned." Yvette, too, blames herself for becoming infected: "All your thoughts are, how could this happen? You know? But look at the situation you put yourself in."

Finally, at the same time as some women found more or less enjoyment in their sexual lives since their diagnoses, others reported no change. Jasmine stated: "Ain't nothing changed. It's all still the same. It's still remain the same, at this point. I'm still the same person, I ain't changed, it's just the diagnosis of illness changed. That's it."

CONCLUSION

This chapter has presented the stories and voices of the women who participated in this project, and is meant to demonstrate the great variety of responses that arose from the interviews. Though the original intention of the research was to look specifically at effects of HIV on sexuality and intimacy, it did not take long to realize nearly all aspects of the lives of these women were influenced by their diagnosis, and that their sexual lives were one of many residual and rippled effects. Difficult lives of drug use, homelessness, incarceration, and inequality led to HIV infections that increased isolation and exacerbated mental health problems. The great deal of stigma existing around the disease created a fear of telling anyone, not just sexual partners, of their diagnosis. Sexuality while HIV positive is fraught with issues of disclosure, fear, condom

negotiation, responsibility, self-blame, and myriad adjustments to what their lives were before. The next chapter will discuss these findings further, and provide recommendations to medical anthropology and public health efforts to lessen further sexual transmission.

Chapter 5: Discussion

INTRODUCTION

It is evident that factors which influence the disproportionate rate of HIV infections among African Americans are as diverse and numerous as the adjustments to one's life after a diagnosis. Stigma and structural violence, two influences on elevated infection rates continue to produce negative outcomes on the lives of the women interviewed, and create a ripple effect into various other areas of their lives including relationships with friends, family, romantic and sexual partners, fear and isolation, and poor mental health. While many of the findings of this research mimic those described in extant literature that focuses on the epidemic of HIV/AIDS in the black community, some areas demonstrated alternative explanations. This chapter will provide a discussion of these disparate findings, as well as provide further analysis into the results presented in the previous chapter.

DISCUSSION

Structural Violence

For the majority of participants, struggles with drug addiction led them down dangerous and harmful paths including sex for drugs or money, legal difficulties, arrests and cycles in and out of prison, and appears to have served as a coping mechanism both before and after their HIV diagnoses. Two women, Sasha and Raquel, mentioned sacrificing their needs or desires to be with a man who provided for them financially, a scenario described by both theories of structural violence (Farmer et al. 2006) and Gender

and Power (Wingood and DiClemente 2000), and are said to contribute to poor health because women may make sacrifices to placate their partners. In addition to Sasha and Raquel's financial constraints, they were fearful of leaving their current partners due to the emotionally dangerous world of dating, which would necessitate disclosure and opening oneself up to judgment and rejection. It is difficult to say whether financial hardship or emotional turmoil was truly a larger deterrent to leave for Sasha and Raquel; both of these women attempted suicide in the past, so it is understandable why preserving their emotional well-being is critical.

Although the current life circumstances did prove difficult for many of these women in terms of limited monthly budgets (most of which were in the form of governmental assistance or benefits), inadequate housing, and reliance upon public transportation, the women did not allow these setbacks to limit their personal agency to the extent which is often portrayed in the literature. Yvette proudly spoke of finally living in her own apartment, something that took her until her mid-40s to obtain. Michelle enjoyed attending educational classes on health including HIV/AIDS and stress reduction. It appears though their situations may remain difficult, they adjust in order to put their health and well-being first, unwilling to sacrifice these things for the sake of a man. This was especially evident with condom use for the purpose of medication adherence, which will be discussed later in this chapter.

Thus, while many of the women in this sample did experience structural violence that placed them at risk for their infection, at this point in their lives most did not allow financial necessity or gender-related power differentials to dictate their health. Even Sasha, who admits keeping her boyfriend around for lack of financial ability to do it on

her own, refuses to have sex without a condom. Therefore, for the most part, there was not a lack of agency among these participants. They tended to make the most of what resources were available to them, especially those available at Francis House, which aided them not only emotionally and socially, but tangibly through the items available at the food bank, and bus passes earned from support group attendance.

Stigma and Social Support

The data collected suggest that stigma was of utmost concern in the lives of the participants due to its ability to permeate their lives so extensively; stigma was the only true commonality identifiable within this group of women. Though the relationship between HIV and stigma is well documented within anthropology and public health literature (Black and Miles 2002; Castro and Farmer 2005; Catz et al. 2002; Clark et al. 2004; Kalichman and Nachimson 1999; Sowell et al. 2003), it remains challenging to quantify the true impact on the daily lives of those infected with HIV. As this study suggests, stigma is the source of various mental, emotional and interpersonal obstacles one has to face when living with HIV. Stigma is the root cause of the self-isolation women described, which created new or exacerbated existing mental health challenges. Its power is overwhelming in the lives of these women, creating shame for their past actions and current disease, and fear of telling anyone of their status, even their children. Four women were too afraid to tell their children of their HIV status, despite disclosure being shown as an important source of emotional support (Edwards et al. 2012).

For the women, the fear of secondhand disclosure meant having doubts about sharing their status anyone, even those they felt were trustworthy. The frustration of women whose family members revealed their serostatus to others through secondhand

disclosure was apparent—something very private was taken from them without their permission. Theories such as the “consequences-based model” proved useful in classifying disclosure patterns, with the potential benefits being weighed alongside possible negative outcomes (Serovich et al. 2008). Fear of rejection was the most consistently mentioned risk when disclosing, but most chose to reveal their status anyway, understanding it as the nature of their current lives.

When it came to sexual and romantic partners, the decision to disclose was based upon the seriousness and potential for longevity they saw with the man. For those who did not meet their partners in a location that would make their HIV status apparent, such as Francis House, disclosure methods included point-blank and stage setting (Serovich et al. 2005). No matter which method was utilized, all appeared anxiety provoking, as these women had rejection in the back of their minds. Fears were mitigated by being selective with partner choice, taking special care to find a man who was looking to get to know these women as individuals, not just for a sexual encounter. This was seen through Yvette and Natasha’s frustrations with men who were interested in a purely sexual relationship. Investing in getting to know one another and having sex for the purpose of love and trust instead of drugs or money were expressed as the foundations for a long-term relationship, the most ideal situation expressed by most of these women. For some though, like Crystal and Raquel, these fears were simply too overwhelming, and led them to reason that being single, without a man in their lives, was easier and less stressful than all that is required when becoming involved with a new partner.

Condom Use

Condoms were used inconsistently in the past relationships and sexual activities of these women, but the majority of participants reported using them with their current partners. Jasmine is the only participant who explicitly stated that never used them, and Natasha insinuated she and her boyfriend used them inconsistently. The seven other participants reported always using condoms with their partners. These results should be interpreted with caution though, as it is socially desirable for participants to report consistent condom use in a setting such as this. Interviewing about topics that are sensitive in nature, especially morally fraught topics like in the case of HIV, it is possible that participants will answer according to what they think is the most socially acceptable response, or what they believe the interviewer wants to hear (Bernard 2006). Further, as a student in public health, participants may have feared admitting to me that they go without condoms. Despite the majority of women using condoms in this sample, there were some who expressed a dislike of them, and varying motivations for their use. Gaining insight into what motivates women to use condoms is useful for promoting their use among others infected or at risk.

The need for condoms to aid in protection against further transmission of the virus is clear. Moreover, condoms help to protect against other sexually transmitted infections (STIs), to which individuals with compromised immune systems have an increased susceptibility. Like HIV, rates of STIs are also elevated among black Americans, with this group exhibiting higher reported rates of Chlamydia, gonorrhea and primary and secondary syphilis in 2011 than any other ethnicity (CDC 2012). As previously suggested, Sobo's (1995) wisdom and monogamy narratives serve as a more useful

discussion tool than theories that posit women sacrifice their health based upon a financial reliance on men (Wingood and DiClemente 2000). This is especially true in the case of Jasmine, who did not use condoms with her partner because they are both HIV positive and are “faithful” to one another. Jasmine’s reliance upon the monogamy narrative is evident here, placing her at risk of becoming infected with an STI if her boyfriend were to expose her to an outside infection. Jasmine feels to use condoms may be “*threatening* expressions of love and intimacy” (Rhodes and Cusick 2000:3, original emphasis). Instead, unprotected sex, a “particularly potent expression of relationship security” (Rhodes and Cusick 2000:10) signaled they had a “complete” and “permanent” bond (Rhodes and Cusick 2000:9). According to Sobo’s monogamy narrative (1995), this boosts the self-esteem of Jasmine, allowing her to project an image of an ideal relationship, rooted in security and trust. Deeper analysis into Jasmine’s reasoning for going without condoms suggests her non-use of condoms for the purpose of STI infection is more motivated by trust; she does not completely deny the possibility of becoming infected with an STI through her partner’s infidelity, because she knows what she would do if this were to happen (she stated that she would kill him). On the other hand, where some women were motivated to use condoms for the purpose of avoiding HIV reinfection, Jasmine did not feel this was necessary due to the fact that neither she nor her boyfriend were on antiretroviral medications. In this case, trust is meaningful in terms of STIs, while a lack of medication meant condoms were unnecessary for prevention of reinfection, presenting a dually motivated choice to go without condoms.

Natasha knew her partner loved her because he pulled out her chairs and opened doors, but even more so because of his willingness to have sex with her without a

condom. His opening himself up to becoming infected—risk taking—translated into a signal of love, fidelity, and trust for Natasha. Crystal, too, expressed that her boyfriend held little concern about becoming infected. Rhodes and Cusick (2000) describe this fatalism as less of a “denial” of infection risk, instead more of an “acceptance of danger as a part of love and life” (12). In these cases, Sobo’s interpretation of risk denial due to a desire to have emotional closeness, trust, and intimacy is applicable, especially considering how Natasha’s self-esteem and self-worth were boosted by her partner’s willingness to become infected due to his love for her. As discussed by Stevens and Galvao (2007), Natasha felt caught between a choice of feeling positive emotions and health, or what she knew was safest for her boyfriend. Emotionally, her desire to please her boyfriend by not always requiring him to wear condoms, alongside of her enjoying his expression of love through willingness to go without a condom conflicted with her guilt and fear that can accompany being the HIV positive partner in a relationship, the one who would be responsible if the infection were passed.

Interestingly, this research challenges literature that suggests sero-positive couples forgo condom use due to reduced concern of passing the virus to their partner (Catz et al 2001; Kalichman 2000; Marks et al. 2009). Kalichman and colleagues (2010) found that awareness of “super-infection,” or “exposure to a new strain of HIV” resulting in “genetic recombination” was great (79 percent of participants; n=389), but did not increase the use of condoms (420). This research revealed conflicting results, as Simone, Michelle, and Sasha were all adamant about condom use *because* of their partner also being positive, motivated by the desire to maintain their current medication regimen and avoid resistance. For Michelle and Simone, whose relationships were presented as

healthy and satisfying, emotional closeness was achieved through their non-sexual interactions as well as sexual. Simone felt comfort in having a boyfriend who she knew would take care of her if she were to become sick. She described him as a someone she enjoyed spending time with, who provided her comfort because it was “less complicated” for her to need to disclose her status or explain why she was sick from time to time. Michelle benefited from her boyfriend’s romantic gestures including flowers, cards, massages, and sharing time together. It is possible that Michelle and Simone’s emotional fulfillment outside of the bedroom negated the need for physical closeness achieved through condomless sex, as in the case of Natasha. Furthermore, as was discussed, the life-extending benefits of antiretroviral treatment were well known by these women, and most appeared quite grateful to have them.

Condom use was one area where the women interviewed demonstrated a great deal of personal agency and strength, explicitly contradicting literature which suggests women lack the ability to stand up for themselves due to entrenched sexism and gender imbalances (Farmer 1999; Wingood and DiClemente 2000). For example, concerning her boyfriend’s attempts to have sex without a condom, Simone described her adamancy with him: “I’m like look, it’s either the condom, or nothing, cause I don’t live here. I can go home. Cause I was doing fine before I even met you.” Sasha, too, says she never tempted to go without a condom: “No! Hell no! Not even on my drunkest night!” Therefore, it seems, the women who chose condoms for the purpose of avoiding medication resistance placed their health at a higher premium than they did the physical and emotional closeness that may be achieved through going with a condom, even when faced with reluctance from their partners.

Though the use of condoms had become the norm in sexual activities for Crystal and Yvette, they both expressed frustration, acknowledging that being infected with HIV meant they condoms were part of their relationships forever. They reasoned that if HIV were not a consideration, they would not have lost the “spontaneity” and “sexual freedom” of their previous sexual lives (Gurevich et al. 2007:18-19). The responsibility of insuring condom use became burdensome for Natasha, who felt her boyfriend ought to be more concerned about his health, especially with the diseases “out there.” Crystal, too, found herself becoming apathetic towards condom use after having to constantly ensure the safety of others. It seems Crystal, Yvette and Natasha were “longing for a former sexual life” when the outcomes of sex were less “mediated by emotional, cognitive, and social considerations” and more by pleasure and enjoyment (Gurevich et al. 2007:26-27).

Sexual Satisfaction and Embodied Experiences

Overall, reported sexual satisfaction varied greatly, with women mentioning it had remained the same, increased, or decreased since the time of their diagnosis. Literature suggests having sex as an HIV positive woman may “become too plagued with anxiety, worry, danger and stress to be pleasurable” (Siegel et al. 2003:447). Among the HIV positive female participants (43 percent African American) interviewed by Siegel and colleagues (2003), celibacy was a safe and easy option for some following their diagnosis, due to the “hassle” of dating, which would require them to open up emotionally and to face disclosure and its potential negative outcomes (Siegel et al. 2003:444). This sample proved similar, with some women, like Michelle, reporting periods of celibacy following their diagnosis. Accordingly, Faith described dating as

bringing too many “headaches,” and consequently, shied away from becoming too close to men for some period of her life. For Michelle and Faith, both dating and the sex it entails appear risky in terms of the “emotional resources,” required (Siegel et al. 2003:444), in addition to the potential for transmission. In the case of Michelle, even the use of condoms proved insufficient in allowing her to relax during sexual activities because she still feared spreading the virus to her partner. Similarly, just as in the cases of Raquel and Sasha that were discussed previously, Natasha and Crystal found themselves more apt to give up on romantic and intimate relationships in order to avoid disclosure, which opened them up to rejection and pain (Siegel et al. 2003). Being on their own was a simpler solution.

For some, the presence of HIV is “always in the bedroom” (Siegel et al. 2003), made it difficult to relax, as was in the case of Sasha, who described HIV as “always here in my mind.” For Yvette, sexual experiences were less satisfying and more anxiety provoking due to concerns over her partner’s reaction rather than her own. Through the use of condoms, she was able to manage her fears of possible transmission, but still found herself worrying about her partner’s thoughts and reactions, hoping he “don’t freak out” during intimate moments.

Associations of sexuality and intimacy with past experiences was also said to diminish sexual interest and participation (Siegel et al. 2003). For Yvette and Sasha, the reduction of their sexual interest was also associated with self-blame; sex was the mechanism by which they became infected with the virus, therefore it was difficult to disassociate and fully enjoy. Along the same lines, Faith found that her current sex reminded her of the past behaviors, when drugs led her to use sex as a means of obtaining

money or feeding her addiction. These examples demonstrate that sexual activity while being HIV positive was never a simple act of intimacy, romance or passion, but a source of apprehension, worry and a reminder of the past.

Michelle and Jasmine were the most vocal about their sexual satisfaction. Michelle experienced increased enjoyment due to the security she felt within her relationship, being in love, feeling fully accepted, and to some extent, using condoms, which allowed the fear of transmission to lessen or dissipate. Jasmine felt her sexuality or intimacy had not been impacted by her diagnosis, therefore felt as satisfied as she was prior to her diagnosis.

Overall, the breadth of topics that arose during interviews demonstrates that experiences of sexuality and intimacy are influenced by far reaching factors, often ones that are extremely distanced from the bedroom. Sexual satisfaction was inextricably tied to emotional satisfaction, fulfillment and closeness. One's mental health, including depression, anxiety, or even the ability to temporarily remove HIV/AIDS from their minds played a role as well. Loving, intimate, and trusting long term partnerships seem to be the mechanism most frequently chosen and desired by these participants as the means to obtain a fulfilling and pleasurable sexual life as a black woman living with HIV.

RECOMMENDATIONS AND FUTURE IMPLICATIONS

1. Social support, particularly emotional support, is essential.

It does not take much time to realize the importance of Francis House in the lives of those who spend time there. The agency became a place to socialize, learn, and seek comfort, advice, resources, and friendship. Still, the extent of isolation and the mental health struggles described during the interviews lead one to believe many people may

delay utilizing organizations such as Francis House. Informal conversations and interviews revealed clients appreciate the non-judgmental safety they find at Francis House, coming from both other clients and staff. Because one must disclose their status in order to gain social support, increasing social support within the walls of AIDS service organizations is certainly more feasible than doing so on the outside.

Existing literature demonstrates the positive effects on health that arise from increased social support, especially in terms of impacts on women's health (Hurdle 2001) and quality of life (Gielen et al. 2001). Strong social support networks provide increased longevity, better coping and healing after illness, a greater likelihood of engaging in preventive health behaviors (Hurdle 2001; Uchino 2005). Additionally, social support has been found to boost medication adherence among HIV positive women (Edwards 2006; Gonzalez et al. 2004). For women in particular, health information is best received from friends or family members via one-on-one communication, especially in the case of sensitive issues such as sexuality (Hurdle 2001). Similarly, partnered or peer support systems are found to increase health behaviors among women (Hurdle 2001).

Francis House may wish to focus on strengthening existing social networks among clients, especially in terms of better communication, or conflict resolution, based upon some of the frustrations clients shared with me. Moreover, a communication workshop or an education session for clients who are part of sero-disconcordant relationships may provide an opportunity for couples to feel more connected, especially considering the importance of Francis House as a source of support for many of the women in this study.

Another possibility is creating a way to welcome and more formally introduce new clients to existing clients. Most clients' behaviors are very patterned—always sitting in the same place and talking to the same people—and increasing social networks may be as simple as opening up a conversation with new clients. This is intended to open communication and build potential avenues for added social support.

2. Knowledge is essential to provide, but is not enough.

Even when condoms were not used or are used inconsistently, it is evident that the women interviewed are well aware that condoms protect them from STIs, reinfection, and medication resistance. Maintaining their health in the present and for the long term served as motivators for them to use condoms, even if their partners resisted. Sasha boasted about her undetectable viral load and was thrilled to have gained back weight she had lost around the time of her diagnosis. Michelle, whose boyfriend is also HIV positive, took pride in the importance of avoiding medication resistance, almost as if it brought them closer to have good health in common. These participants knew the value of their medication as a source of extending their lives, and appeared unwilling to take this risk at the expense of compromised health.

In terms of public health, and health education in particular, studies such as this are useful to better understand *why* women go without condoms. This information can then be used for the design of programs to encourage their use. Further, typical discourse of condom promotion suggests the use of condoms for protection from STIs or to decrease transmission of the virus to others, but this research offers that the desire to remain on a consistent antiretroviral medication regimen may be more meaningful to women.

For women like Michelle, Sasha, and Simone, looking beyond the momentary passion or pleasure of having sex without a condom seems to be inspired by long-term drivers, especially maintaining their current medication regime. In terms of the Social Cognitive Theory, Michelle, Sasha and Simone all hold sufficient self-efficacy to influence their behavior, and their environment via the behavior of their partners, who are all willing to use condoms. In order to benefit those who may truly be struggling with asserting themselves against partners who prefer condomless sex, delving into how Michelle, Simone and Sasha are able to accomplish this, and how these skills could be taught to others may be a critical step in health education efforts. The informal peer to peer information sharing that occurs at Francis House daily (in both support groups and during casual conversations) is useful for many, and may be useful if formalized into a workshop or a “topic of the day” support group discussion. Therefore, those with higher self-efficacy could share their techniques and success stories, creating a supportive environment to help others with less self-efficacy to be able to utilize condoms more consistently.

Alternatively, cases like Jasmine, who feels it is unnecessary to use condoms with her HIV positive boyfriend due to neither of them being on an antiretroviral regimen is more challenging; she either does not feel threatened by or is denying the possibility that she may be at risk for an additional infection. In this case, Jasmine feels confident in her ability to assert herself and knows he is well aware that she would lash out violently if he were caught cheating, but simply does not believe condoms are necessary. Using the Health Belief Model to raise Jasmine’s perceived susceptibility to STIs, the perceived severity of contracting additional infections while HIV positive, while emphasizing the

perceived benefits of condom use may be one route to addressing her non-use of condoms with her partner (Rimer and Glanz 2005).

Ethnographic studies are particularly useful for making sense of “behaviors that might otherwise appear irrational, meaningless, or inscrutable, or go unknown” (Singer and Baer 2007:52). Further, when health promotion is designed to be important or meaningful in the lives of the target audience, they are more likely to be adopted, even if they are not directly health related. For instance, for Natasha, her boyfriend’s willingness to go without a condom was a signal of love and created feelings of intimacy for her. Therefore, to use condoms may be seen a threat to this sense of security gained from forgoing their use. This is only one example of how seemingly “irrational” decisions are made based upon one’s emotional experiences, and what is meaningful in their lives. For example, among the women who are scared to tell their children about their HIV infection, it was evident that they were strongly emotionally invested in holding onto that relationship. With this in mind, moving beyond physical health and towards an emotionally significant aspect of the women’s life, such as living longer for their children, may be more consequential in changing behavior than future health outcomes.

3. Provide Francis House clients with more informational and appraisal support that is meaningful to them.

This research project and the questions it sought to answer were not informed by previous time spent with this population, thus, in hind-sight, sexuality and romantic relationships do not appear to be the most impacted or challenging aspects of the lives of women living with HIV/AIDS. Instead, stigma, isolation, poor mental health, and struggles of daily living (i.e., housing, transportation, maintaining sobriety) were often

the focus of interview discussion, and brought about more emotional response than sexuality. While it would be easy to suggest organizations and programs focus on attempting to change what is well known about stigma, depression and isolation, it is unrealistic to expect such deeply rooted issues to be addressed easily or quickly.

Participant observation showed that those in attendance at Francis House were, for the most part, very interested in what outside speakers had to say. Often, speakers were representatives of pharmaceutical companies, and tended to focus on the importance medication adherence, and other biomedical topics. While important, guest speakers of other disciplines can bring a fresh perspective about methods of coping with mental health and stigma to clients, offering alternative perspectives from those they receive on a day-to-day basis from one another and Francis House staff. Speaker or workshop topics could include: disclosure to others (may even have separate workshops for specific audiences: romantic and sexual partners, friends, family, and children), gaining support/resources, holistic health (maybe even a walking group or healthy cooking techniques), dealing with mental health struggles, or even more optimistic topics, such as becoming an advocate.

LIMITATIONS

This study is not without its limitations. First, small sample size (n=9) makes consistent patterns indiscernible, and therefore the results are not generalizable to all black women infected with HIV/AIDS. Secondly, social desirability bias may have skewed the results of the study due to the nature of the topic. Finally, a convenience sample of individuals who are all Francis House clients may have produced results different than a sample of women who did not attend support groups or utilize any of the

other resources offered there. In some respect, clients who utilize Francis House are seeking out their services, and therefore may be self-selecting, a source of bias in studies. In light of the recommendations to increase social support, it is possible that Francis House clients have much more social support than others living with the virus, simply due to their attendance to support groups and other Francis House meetings.

ETHICAL CONSIDERATIONS

Working with a population infected with HIV/AIDS, a disease that continues to be a source of stigma, discrimination, stereotypes, and misinformation, means special consideration must be taken to protect the identity of those who participated in this research. Care was taken to not share details which would allow staff or other clients to identify any of the women who bravely participated in these interviews, especially considering the personal nature of the questions asked and topics that arose. In a few instances, women shared moments or stories that would have perfectly demonstrated a theme or concept of note, but writing about it in this type of permanent record would have compromised the anonymity that was promised to those participating. As an anthropologist, the study of and writing about others is, to some extent, a “selfish” endeavor (Farmer 2009:184). After all, much anthropological writing, as well as academic writing in general, is done for our peers (Farmer 2009). Thus, to risk revealing the identity of a participant cannot be justified for the sake of writing about a perfectly poignant moment.

It is important to note that Joy Winheim, the director of Francis House, gave permission for use of the name of the organization in this thesis. Using the organization’s name, as well, potentially creates an opportunity for identification of participants.

Therefore, extra caution was taken to not provide too many descriptive details of the women in this study.

DISSEMINATION OF RESULTS

The results of this study, though not generalizable to a larger population, may be useful for Francis House staff in order for them to gain a better understanding of client sexual decision-making, and of the many troubles they face in terms of stigma, mental health, and isolation. These are exacerbated not only by being infected with HIV, but frequently by the mark of poverty in a socially inequitable society, struggling to fight their addictions and maintain sobriety, and differential access to many resources as well. While Francis House does work to address what is feasible, such as providing bus passes, a food pantry, and qualified professionals on staff, as an anthropologist, I may be able to provide alternative explanations or viewpoints gained through this research. A copy of the final thesis manuscript will be provided for Francis House to keep as a record. If desired by the staff, a presentation and accompanying document could be made with a summation of results and recommendations, and would provide an opportunity for them to ask questions they feel I may be able to answer because of this research. Also, it may be useful to provide a shortened version of this manuscript, particularly the results and discussion section, so that Francis House staff could read of the results and the researchers conclusions more rapidly.

After all interviews were completed, a presentation was given to Francis House clients in lieu of their daily support group. Much of this presentation was an opportunity to show appreciation for the clients being so willing to accept my presence and for sharing their space, time, and lives with me. In order to protect the identities of

participants, many of whom were present during this time, stigma was the only theme from the research that was discussed in this presentation. This was also done because stigma is a problem that affects both males and females with HIV, and is therefore applicable to many of the clients. With this in mind, clients were encouraged to use their infection for further advocacy and activist work. As a closing activity, clients were asked, “If you could tell the general population one thing about HIV/AIDS, what would it be?” Below are some of the answers received during this vibrant discussion:

- “God infected me because he knew I could handle it.”
- “Knowledge is power. Ignorance does not exempt you from responsibility.”
- “Doesn’t matter how you get it, it’s what you do with it. Nasty people label you real quick. People are not dying no more with HIV.”
- “HIV don’t jump.”
- “Wear condoms.”
- “Stop being ignorant to the fact that you [are not] exempt from this disease. You are at risk. STDs. Get your family members tested. How do you know that he doesn’t have it?”
- “HIV is not tailor made. It can fit the president as well as it can fit a hustler.”

This brief and informal free listing exercise allowed Francis House clients to voice what they feel is most bothersome about living with HIV, and to make suggestions to others who are not living with the disease, especially those who are in denial of their risk of becoming infected. In many ways, it demonstrates the stigma they face (“Nasty people label you real quick”) and how their infection serves as an argument against people who think it could never happen to them (“HIV is not tailor made”). This small

sample seems to focus on the vulnerability of anyone, not just those engaging in “high risk” behaviors.

FUTURE RESEARCH

After completing this research, it became evident that it was not just sexual relationships that were impacted in the lives of these women who live with HIV, but nearly *all* their relationships—familial, friendships, and with acquaintances. Thus, in hindsight, a broader look at disclosure patterns, timing, and techniques may have revealed a better understanding of how women make sense of their infection in relation to other people in their lives. Idealistically, preliminary research at the facility finding out what Francis House clients deemed problematic or important within their community, using methods and theories such as Participatory Action Research or Community Based Participatory Research, would have been more fruitful in terms of research application.

Other areas of research that may be beneficial to understanding the psychosocial impacts of living with HIV/AIDS include: 1) women who purposefully choose celibacy after diagnosis; 2) a comparison of the impact of race and gender on stigma, specifically, being a white gay male versus being a gay black male; 3) experiences of those living with their serostatus fully “out,” as is frequent among HIV/AIDS activists; 4) the impact of being a client in an AIDS service organization; and 5) the experience of belonging to a community that is highly researched, such as those living with HIV/AIDS.

CONCLUSION

As has been extensively documented in the literature, structural, societal, cultural and interpersonal factors work simultaneously to create an environment where black Americans are at an increased risk of becoming infected with the HIV/AIDS virus. This

has resulted in disproportionate rates of infection for African Americans, who are faced with the additional struggles of living with HIV/AIDS in addition to the environment that facilitated their infections.

For most of the women interviewed as part of this research project, earlier life experiences with drugs, alcohol, abusive relationships, and dysfunctional households set the stage for their current situations. They fight to maintain their sobriety and ward off bouts of depression, exacerbated by a stigmatizing condition that leaves them fearful to reach out for help. Disclosure may translate onto increased support, but it also may mean the loss of a friend, family member, or partner, and the shame and pain of being rejected. In terms of sexuality, some of the women chose to find others like them, also HIV positive, so as to avoid having to explain their status or face the possibility of their partners walking away. The women knew they should use condoms since they could transmit the virus or become re-infected with other strains that could potentially be resistant to the drugs the women were receiving. Nevertheless, the condoms were undesirable for those who saw them as the opposite of closeness, intimacy, trust and spontaneity. For others, condoms served as their mechanism to relax during sex, removing the fear that they could spread the virus to their partners.

Despite the resiliency and willingness to fight their illness and the ignorance around it, the women who participated in this study could certainly benefit from an increased feeling of support. Living with HIV creates challenges unique to those who are positive, and building up the networks within the “HIV community” is essential to creating strong ties. Ideally, this would prevent black women from isolating and retreating into themselves, and would provide them with a safe environment in which

they could discuss their feelings, experiences, disappointments, and hopefulness around those who can truly empathize with them.

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Appendix A: Screening questionnaire

This questionnaire will gauge your eligibility to participate in the study *Experiences of intimacy and sexuality among HIV positive black women*. After completion, you will be told whether or not you are eligible to participate. At this time I am unable to inform you of why you were or were not able to participate in this study, though I am happy to inform you of the inclusion criteria once the study has concluded. I can be reached at (859) 539-5949.

Some of these questions are personal in nature. You are free to refuse to answer any or all questions, but doing so may disqualify you from participating.

Demographics

1. What is your date of birth?
2. Age:
3. What is the highest level of education you've completed?
 - a. Some high school
 - b. High school graduate/GED
 - c. Some college
 - d. College graduate
 - e. Advanced degree
4. Are you Hispanic or Latina?
 - a. Yes
 - b. No
 - c. Refuse to Answer
5. Would you describe yourself as white?
 - a. Yes
 - b. No
 - c. Refuse to Answer
6. Would you describe yourself as black or African American?
 - a. Yes
 - b. No
 - c. Refuse to Answer
7. Would you describe yourself as Asian?
 - a. Yes
 - b. No
 - c. Refuse to Answer
8. Would you describe yourself as Native Hawaiian or Pacific Islander?

- a. Yes
 - b. No
 - c. Refuse to Answer
9. Would you describe yourself as American Indian or Alaska Native?
- a. Yes
 - b. No
 - c. Refuse to Answer
10. Would you describe yourself as Other?
- a. Yes
 - b. No
 - c. Refuse to Answer

HIV

11. In what year were you diagnosed with HIV? (OR at what age were you diagnosed?)
12. How did you contract HIV?
- a. Sexual contact
 - b. Injection Drug use
 - c. Perinatally infected
 - d. Don't know
 - e. Other
13. Do you know your most recent viral load?
- a. Yes _____
 - b. No (follow up: do you remember being told you are “undetectable”?)
 - i. Yes
 - ii. No
 - iii. Don't Know
 - c. Refuse to Answer

Health

14. Would you say that in general your health is:
- a. Excellent
 - b. Very Good
 - c. Good
 - d. Fair
 - e. Poor
 - f. Don't Know
 - g. Refuse to Answer
15. Now thinking about your physical health, including physical illness and injury, for how many days during the past 30 days was your physical health not good?
- a. Number of days _____
 - b. Don't Know
 - c. Refuse to Answer

16. Now thinking about your mental health, including stress, depression, and emotions, for how many days during the past 30 days was your mental health not good?
- Number of days _____
 - Don't Know
 - Refuse to Answer
17. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as taking care of yourself, working, or doing things for fun?
- Number of days _____
 - Don't Know
 - Refuse to Answer

Sexuality

18. When was the last time you had vaginal or anal sex, with vaginal sex being when a man inserts his penis into a vagina, and anal sex being when a man inserts his penis into an anus?
19. When you had sex on that date, who was this person to you?
- Husband
 - Main partner/Boyfriend
 - Casual partner
 - Someone you have sex with in exchange for other things
 - Other
20. When was the first time you had sex with that person?
21. When was the last time you had sex with someone for the first time?
22. On a scale from 1 to 10, with one being not at all satisfied, and ten being extremely satisfied, how satisfied are you with your current sex life?

Appendix B: Semi-Structured Interview Guide

Interview date: _____

1. To begin, tell me a little bit about yourself.
2. Tell me about how being HIV positive has affected your life.
3. What were your romantic and sexual relationships like before your diagnosis?
4. How does this compare to your romantic and sexual relationships now that you are living with HIV?
5. Tell me about your sex life within the past 3 months.
 - a. Follow up: When you decide to become sexually involved with your most recent sexual partner, did you tell them about your HIV status?
 - i. If no: Why didn't you tell? What kept you from telling him?
 1. What's your experience during sex knowing you haven't told your partner about your status?
 - ii. If yes: How did you decide when it was the right time to tell?
 1. How did you tell them? How did he react?
 2. OR
 3. What's his HIV status? Does this make a difference in your experience/enjoyment?
6. Tell me about using condoms with your partner(s).
 - a. Follow up: How often do you use condoms?
 - i. How does he feel about (not) using condoms?
7. How do you think your experience with alcohol and other drugs has affected your sexual experiences?
 - a. Follow up: Does this change how you tell your partner of your status?
 - i. Does this change your use of condoms?
8. Talk to me about the HIV disclosure laws that require you tell your partner about your status before sexual contact. How do you think this affects your decisions to disclose or not?
9. What is it like to have sex as a woman living with HIV?

10. Has your definition of intimacy changed since you became HIV positive? How?
11. How do you think this is different from the experience of HIV positive men?
12. Do you feel that being HIV positive has changed your satisfaction from sex? How so?
13. Is there anything else you would like to tell me about your experiences with HIV?

Appendix C: Proof of USF IRB Approval

4/7/13

University of South Florida Mail - eIRB: Study Approved



Mackenzie Tewell <mrt@mail.usf.edu>

eIRB: Study Approved

eirb@research.usf.edu <eirb@research.usf.edu>

Tue, Jun 26, 2012 at 7:25 AM

Reply-To: eirb@research.usf.edu

To: mrt@mail.usf.edu



IRB Study Approved

To: Mackenzie Tewell
RE: Sexuality among HIV positive black women
PI: Mackenzie Tewell
Link: [Pro00008313](#)

You are receiving this notification because the above listed study has received Approval by the IRB. For more information, and to access your Approval Letter, navigate to the project workspace by clicking the Link above.

WARNING: DO NOT REPLY . To ensure a timely response, please do not reply to this email. Direct all correspondence to **Research Integrity & Compliance** either through your project's workspace or the contact information below.

University of South Florida
Division of Research Integrity & Compliance - Office of Research and Innovation
3702 Spectrum Blvd Suite 155 - Tampa, FL 33612

Template:_000 - IRB Study: Approved

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1/1