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Issues Affecting Sexual Decisions among Black Women in the Era of HIV/AIDS

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Abstract

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by

Saecilia Jackson

MA, University of Phoenix, 2003

BS, University of South Alabama, 2001

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

HIV/AIDS became a significant concern in the United States (U.S.) during the 1980s and in recent years has increased the most among people living in underserved urban areas, particularly impacting Black women ages 24-35. Guided by the social learning theory, this phenomenological study explored the lived experiences and behaviors of Black women in the south in order to understand their sexual health decisions and how those decisions impact the spread of HIV/AIDS among this group. The central research question focused on understanding the sexual decision making of Black women in Georgia, from the perspective of the client and provider. Convenience sampling was used to recruit 21 participants at 2 HIV testing facilities. Interview data were collected from 9 clients, consisting of Black women ages 24-35, and 12 providers, consisting of HIV testing coordinators and administrators. Data were subjected to an inductive coding procedure and were then organized around themes. Findings suggest that clients perceived a lack of education and limited access to healthcare, due to socioeconomic status and rising medical costs, as contributing factors to the sexual decisions of Black women. Providers differed in suggesting that community distrust and lack of provider empathy and awareness were the primary factors due to broken relationships between provider and client. By understanding the sexual decision making of Black women in Georgia, this research can foster social change by identifying and creating educational programs heavily focused on the delivery of positive sexual health messages aimed at reducing the spread of HIV/AIDS among this group.

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Dedication

This research study is dedicated to all of those who feel that their voices are limited. You were created to shine.

Acknowledgments

I would like to start out by thanking my husband, Reginald Jackson for his support and love in guiding me through my program. He is my backbone and has offered tremendous support throughout my time at Walden. I would also like to thank my children Sanaa and Christian for being my glimmer of hope during my heaviest times. They make me push harder to provider a brighter future for them. Lastly, I would like to thank my mom, dad, family and friends for their well wishes and support throughout this journey.

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Chapter 1: Introduction to the Study

Introduction

The human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) are diseases that have affected over 35 million worldwide (Aids.gov, 2015). During the 1960s and 1970s, the first appearance of HIV within the United States (U.S.) was detected. The virus was initially determined to come from Africa and was believed to have derived from human contact with chimpanzees infected with the simian immunodeficiency virus (SIV) (Theaidsinstitute.org, 2015). Most scientists believe that HIV originated from the cross-species transmission of SIV from primates to humans, while a minority of people think HIV was created by scientists with nefarious intent (Nattrass, 2012). Clusters of the disease began to show up in the U.S. during the 1980s and it was during this time that it grew to become an epidemic, primarily among the homosexual White men community (Cantwell, 2003). In the decades following, the course of the disease has changed from one affecting primarily White homosexual men to one affecting people primarily in urban, underserved communities in the southern U.S.

Research suggests that socioeconomic status, race, gender, geographic location, sexual orientation, and exposure to discrimination inform people’s sexual health behaviors and decision making (World Health Organization, 2015). In Georgia, Blacks made up 77% of new HIV/AIDS diagnosis in 2009 (Southern HIV/AIDS Strategy Initiative, 2012). Black women accounted for 29% of estimated new HIV infections among all adult Blacks in 2010 and most HIV infections among Black women are attributed to heterosexual contact (Kff.org, 2015). Understanding how these factors shape southern Black women's sexual health is vital to bridging the gap between communities of color and the medical field as they work toward the common goal of reducing the spread of HIV/AIDS.

Background

AIDS is now the leading cause of death among Black women aged 24-35 (Cdc.gov, 2015). Data shows that the south has witnessed a large increase in the number of HIV infections among the general Black population at a rate 61% in 2011 (Southern HIV/AIDS Strategy Initiative, 2012). This growth is due, in part, to policy disparities, which are rooted in learned behaviors and related to matters of class, race, gender, location, and sexual orientation, as well as enduring stigmas around HIV/AIDS.

Demographic Disparities

Socioeconomic Status.

Socioeconomic status (SES) is often associated with the social class of an individual or group of people, and is measured through a combination of income, education, and occupation (Apa.org, 2015). Socioeconomic disparities and classism negatively affect those who are of low socioeconomic status. People who have low SES can often internalize the dominant wealthy group's beliefs and attitudes towards them and play those beliefs against themselves and others within their class (Class Action, 2010). Low SES correlates to less institutional access, fewer economic opportunities, lower levels of educational attainment, and poor health (Class Action, 2010). With HIV affecting those of a lower SES disproportionately, many low income individuals are left with few or no treatment options (Apa.org, 2015). A person's SES also affects the relative risk of HIV infection. Lacking economic resources is linked to riskier health decisions. Also unstable housing due to lower SES is associated with a greater chance of IV drug use, which in turn can increase the risk of unsafe sexual behaviors (HIV/AIDS & Socioeconomic Status, 2015).

Poverty rates for Blacks and Hispanics greatly exceeded the national average of 15.1% in 2010 (Npc.umich.edu, 2015). In 2010, 27.4% of Blacks and 26.6% of Hispanics were poor, compared to 9.9% of Whites and 12.1% of Asians (Npc.umich.edu, 2015). Around 43.6 million Americans were living in poverty in 2009 with an increase of poverty rates for Blacks to 25.8% (Npc.umich.edu, 2015). In 2013, Blacks made up 27% of the poverty rate in Georgia as compared to Whites who made up 10% (Kff.org, 2015).

Race and Gender.

The U.S. Office of Minority Health (OMH) stated that Black women contract AIDS at 23 times the rate of White women, and Black women are 15 times more likely to die from HIV/AIDS as White women (2015). Black men have almost 7.8 times higher rates of HIV/AIDS than White men (Minorityhealth.hhs.gov, 2015). The high rate of transmission for this disease among Blacks showcases the growing disparities between ethnicities. Black women are seeing an increased infection rate of HIV/AIDS and it has turned into a phenomenon that has surpassed many of the health issues that other races and genders are facing in today’s society (Minorityhealth.hhs.gov, 2015).

Location.

The south has dealt with many issues in relation to the increase in HIV/AIDS cases. Some of those issues consist of limited/no transportation due to rural locations and limited/non-medical coverage, which has contributed to lack of medical services among clients. In 2005, half of all AIDS-related deaths in the United States were in the south, and half of all Americans with HIV lived in the region in 2006 (Southernaidscoalition.org, 2015). Nine of the 15 states with the highest HIV diagnosis rates were southern states, with 45% of all new infections coming from that area (Southernaidscoalition.org, 2015). Southern Blacks are uninsured at rates that greatly exceed Whites at 28.5% versus 18.5% of Blacks respectively. Some of the variables that affect the HIV rates in southern and rural areas include reduction in Medicaid coverage, decrease in rural case management services, reduction in local HIV healthcare providers, and decrease in funding for areas that have the highest transmission rates.

Sexual Orientation.

In 2010, Black bisexual and gay men who have sex with men (MSM) accounted for an estimated 72% of new infections among all Black men (Cdc.gov, 2015). Some Black men choose to hide their MSM behavior out of fear of the rejection they may receive due to the homophobia they may encounter (Cdc.gov, 2015).

Based on the high HIV/AIDS prevalence among Black women, many researchers have suggested that a “bisexual bridge” of transmission is transferring HIV from the Black MSM community to Black heterosexual women (Dodge et al., 2010). Blacks also tend to have sex with partners of the same race/ethnicity, which is why they face a greater risk of HIV infection with each new sexual encounter (Cdc.gov, 2015). In the deep south, the percentage of HIV diagnosis among Black MSMs increased from 26% in 2008 to 29.9% in 2011 (Southernaidscoalition.org, 2015). This, in turn, leads to an increase in the number of HIV infections among Black women, specifically in the south (Southernaidscoalition.org, 2015).

Policy Issues.

HIV/AIDS discrimination exists worldwide, although that discrimination manifests itself differently across countries, communities, and cultures (Avert.org, 2015). The stigma of HIV/AIDS can foster fear among those who are not educated on the specifics of the disease. Government enforced stigma related to HIV/AIDS is commonly manifested in the form of laws, policies, and administrative procedures, which are often justified as a necessity to protect the "general population" (Attawel, Pulerwitz, & Brown, 2002). On a national level, defunding of sexual health programs along with medical costs and premiums can have an effect on the treatment of those infected with the disease. Government reinforced stigmas can also deter the government from taking swift action against the epidemic (Avert.org, 2015).

With the introduction of the Affordable Care Act (ACA) in the U.S. in 2010, there have been mounting concerns about the affordability of healthcare and the impact of healthcare costs on decisions about sexual health. The ACA is a comprehensive health insurance reform that allows consumers to have control over the health care that they choose (HHS.gov, 2013). People who are infected with HIV/AIDS may suffer from violations of their rights, such as government stigma and discrimination in relation to access to health, education, and social services (HHS.gov, 2013). This is the reason why many, specifically within the Black community, fail to get tested or educated about HIV and, therefore, engage in high risk sexual behaviors that increase their risk of HIV infection. The ACA can have positive implications for people at risk and living with HIV/AIDS by improving access to coverage for those with preexisting conditions, offering preventive services, and expansion of the healthcare delivery system (Aids.gov, 2015)

Statement of Problem

Black women in the south are facing growing health disparities, including limited access to healthcare, rising healthcare costs, defunding of sexual health programs, and discrimination. HIV/AIDS transmission among Black women is an on-going phenomenon affecting their overall sexual health and life span. CDC statistics show that from the beginning of the HIV/AIDS epidemic until 2011, Blacks accounted for a majority of the cases in the United States, with Black women representing an estimated 29% of new HIV infections in 2010 (2015).

Over the past few years, HIV/AIDS has drastically impacted many disenfranchised urban communities. Although Blacks make up only 14.2% of the U.S. population, the rate of new HIV infection among this population is eight times than that of Whites (CDC, 2013). In 2010, the rate of Black women living with an HIV infection diagnoses in Georgia was 12.2 times that of White women (AIDSVu, 2015).

Recent public policy measures have effectively eliminated many programs within the Black community, greatly impacting the potential support that Black women could access to increase their knowledge and improve their sexual health (Amutah, 2015). There is a vast amount of research detailing the HIV/AIDS epidemic among Black women, utilizing a narrow range of demographic variables (Dodge et al., 2010). Yet there is there is scant research addressing the myriad demographic issues that inform sexual decision making among Black women, such as matters related to disparities by class, race, gender, location, sexual orientation, and exposure to HIV/AIDS stigma from a general perspective (Dodge et al., 2010). The Obama administration has taken steps in eliminating racial disparities through the National HIV/AIDS Strategy and Implementation Plan but there is still more work to do in conducting research on the behaviors that lead to the transmission of HIV/AIDS (Dodge et al., 2010).

Purpose of the Study

The purpose of this study is to better understand the sexual health experiences of Black women in Georgia as they relate to HIV/AIDS. The study adopts a qualitative approach to explore individuals' sexual health (i.e., sexual decisions and other behaviors) and how sexual health may be influenced by experiences of stigma and discrimination in the age of HIV/AIDS. In so doing, this research aims to uncover how healthcare practices and policies affect Black women's lives.

There are many resources that detail the inadequacy of HIV/AIDS prevention education for Black women, but there is not much data about the broader demographic and policy context facing many of these women. By unearthing the deeper meanings southern Black women ascribe to their sexual health, this research can inform targeted policy and best practices aimed at HIV/AIDS prevention.

Research Questions

The assumption of this research is that healthcare policies and demographic factors shape how Black women living in Georgia approach their sexual health, including how they address HIV/AIDS in their lives. The central research question of this study is: What are the shared experiences of sexual health among Black women in Georgia, specifically from the perspective of both patients and healthcare providers*?* Specific research questions include: How do Black women in Georgia make sense of their sexual health decision making and behaviors within the shifting healthcare climate? In what ways do stigma and discrimination inform these women's sexual lives given the climate of HIV/AIDS in the south?

Theoretical Foundation

This study utilizes the social learning theory developed by Albert Bandura (1977). Bandura's theory emphasizes the importance of observing and modeling the behaviors, attitude, and emotional reactions of others (Bandura, 1977). Observational learning is one component of the social learning theory and states that people can learn by watching other people perform their behavior. There are three basic models of observational learning which include a live model that focuses on an actual person performing a behavior, a verbal instruction model that involves telling of details and descriptions of a behavior, and a symbolic model that includes either a real or fictional character demonstrating the behavior via movies, television, books, online media and other sources (Bandura, 1977).

Based upon this first component of the social learning theory, people's behaviors can be affected by their environment. This can include sexual choices being made based upon what people may see within their community, school, and at home. With the overabundance of sexual themes via television, music, books, and face-to-face interactions, Black women have a good chance of observing behavior that can possibly increase risky sexual decisions and behavior (Bachanas, 2002).

A second component of the social learning theory includes the modeling process, which focuses on helping people understand that not all observed behavior could be learned effectively, and learning may not always result to behavioral changes. The process includes attention, retention, reproduction, and motivation as steps to determine whether social learning is successful or unsuccessful. An example of Bandura's model is listed in Figure 1.

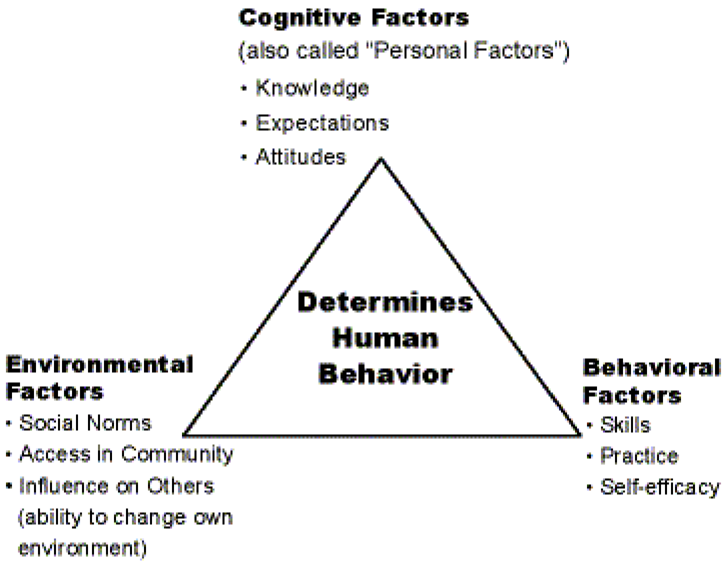

Figure 1. An example of the social learning theory model. Reprinted from Theories and Approaches, In *Resource Center for Adolescent Pregnancy Prevention*, n.d.,Retrieved March 5, 2015 from http://recapp.etr.org/recapp/index.cfm?fuseaction=pages.TheoriesDetail&PageID=380 Copyright 2007-2015 by ETR. Reprinted with permission.

Some sexual decisions among Black women are modeled after certain behaviors (Bachanas, 2002). This modeling includes mimicking behaviors that they may have observed in their community, school, and at home. Environmental factors play a major role in the choices that Black women make in regards to their sexual health and how they decide to “physically” act out on those observed behaviors (Bachanas, 2002).

Significance of the Study

This study explores the perceptions of providers and Black women clients in the south about the nature of the latter group’s sexual health decision making and related behaviors. This study considers how demographic disparities inform these women’s sexual lives in the era of HIV/AIDS. The results of this study contribute to a deeper understanding of the policy and social contexts shaping southern Black women’s sexual lives.

The results of this study will be presented to policy makers and community activist organizations and will offer suggestions for increasing sexual knowledge and better access to health care. With this new knowledge, healthcare professionals can develop more appropriate policies and practices that avoid stereotypes and discrimination, factors that currently are shown to facilitate the spread of HIV/AIDS (Ohchr.org, 2015). The results could also be used to help fill a gap in literature regarding demographics and policy concerns and provide a starting point for deeper dialogue around HIV/AIDS within the Black community (Dodge et. al., 2010). The results of this study could lead to policy initiatives that focus on funding for medical care expansion for those with limited or no income, increased education programs (including sexual health), and elimination of stigmas associated with the disease.

Definition of Terms

Acquired Immune Deficiency Syndrome (AIDS): The final stage of HIV infection where people have badly damaged immune systems, and they are at high risk for opportunistic infections (Aids.gov, 2015).

Centers for Disease Control (CDC): Key division of the Department of Health and Human Services providing a system of surveillance to monitor and prevent disease outbreaks, implement disease prevention strategies, and maintain national health statistics (Cdc.org, 2015).

Classism: Systematic assignment of characteristics of worth and ability based on social class (Class Action, 2010).

Demographics: The statistical data of a population, especially those showing average age, income, education (Dictionary.com, 2015).

Discrimination: Treatment or consideration of a person or thing based upon the group, class, or category to which that person belongs rather than on individual merit (Dictionary.com, 2015).

Human Immunodeficiency Virus (HIV): A virus that can lead to acquired immune deficiency syndrome (AIDS), which, the human body cannot recover from (Cdc.org, 2015).

LGBT: Lesbian, Gay, Bisexual, and/or Transgender.

Male Sex with Men (MSM): Men who have sex with other men who may or may not identify as homosexual or bisexual (JournAIDS, 2014).

Policy: A level overall plan embracing general goals and acceptable procedures, specifically of a governmental body (Merriam-webster, 2015).

Simian Immunodeficiency Virus (SIV): Primate lent virus that infects no fewer than 36 different non-human primate species in sub-Saharan Africa (Sharp, Shaw & Hahn, 2005).

Socioeconomic Status (SES): Social standing of a class, individual, or group (APA, 2014).

Delimitations

For this research, Black women over the age of 18 in Georgia were targeted for participation in the study in an effort to uncover how they view their sexual health, including perspectives on HIV/AIDS. To only study HIV-positive Black women would not provide a comprehensive understanding of the underlying issues and behaviors that lead to high-risk sexual decisions. HIV testing coordinators and administrators (which included Black women) from HIV testing facilities were also selected to participate in the study as a means to identify and better comprehend how stigma and discrimination may be related to HIV/AIDS healthcare. The study was limited to Black women and HIV testing coordinators and administrators in Georgia because of the rising rates of HIV/AIDS in this region as compared to other southern states. Given the diversity of SES among the Black women clients and HIV testing coordinators and administrators who participated in the study, the findings can be generalized to Black women and HIV testing coordinators and administrators within the south.

Limitations

One limitation of this study involves HIV-positive women who agreed to participate in the study and related privacy concerns about the safety of their health information. This concern may have caused a number of potential participants to decline to participate in the study. In order to ensure participants that their information would be protected, a copy of the Health Information Privacy Act (HIPAA) in appendix d was provided to participants to assure them that certain information would not be disclosed without their informed consent. A second limitation was the diversity of staff among HIV testing facilities and the crossover of Black women clients and Black women HIV testing coordinators and administrators. The last limitation was getting truthful information from healthcare workers without fear of being ostracized at their jobs. In order to ensure their participation in the study, participants were reminded several times that their identities and the data they provided would be rendered anonymous.

Social Change Implications

An analysis was completed, which included historical data that was connected to specific data on the rates of HIV/AIDS among minorities and Black women, peer-reviewed articles, and the interview results of a convenience sampling of healthcare workers of all ages and races along with Black women. The purpose of the interviews was to explore factors that contributed to the sexual decisions of Black women living in Georgia in the era of HIV/AIDS. Data collected from the interviews was used to identify policy and demographic variables that affect the sexual decisions of Black women. This information can be used by government officials, nonprofit agencies, medical institutions, and local citizen groups to decrease the spread of HIV/AIDS among Black women. The findings from this study could contribute to positive social change by formalizing an increased awareness of the issues affecting the sexual behaviors of Black women. It could also reduce stigma and discrimination among this group by providing program sustainability that will provide the education needed for Black women to protect themselves against the virus.

Summary

HIV/AIDS continues to affect Black women at a disproportionate rate when compared to other demographics. Women account for one in four of all new HIV infections, and of those new infections, two in three are Black women (Minorityhealth.hhs.gov, 2015). Demographic disparities by SES, race, gender, sexual orientation, and location, as well as experiences of stigma and discrimination against those with HIV/AIDS influence the likelihood of new infections among southern Black women.

The south has seen the largest increase in HIV/AIDS infection among Black women. With the introduction of ACA, healthcare costs play a growing role in people's sexual decision making (Hhs.gov, 2015). The disproportionate number of HIV/AIDS cases in the south is caused by many factors, including lack of access to healthcare, widespread poverty, deficient HIV testing and education, a shortage of accessible medical specialists in rural areas, and persistent prejudice among many in the south against homosexuality (Kohn, 2015). The role of stereotypes and the effects of discrimination are important in understanding how to better serve those in urban, underserved communities, especially Black women.

Chapter 2 reviews the literature on demographic issues and policy concerns on the issue of HIV/AIDS among Black women. An overview of research on the social learning theory is discussed in relation to HIV/AIDS concerns among Black women, and similar studies that have used this theoretical approach are discussed. Methodologies used in the literature are examined, with specific focus on similar concepts, as well as where a gap remains among extant research.

Chapter 2: Literature Review

Introduction

"It is time for the African American Community to face the fact that AIDS has become a Black disease and find ways to defeat it," said the chairman of the NAACP at the 16th World AIDS Summit in Toronto, Canada (Horton, 2013, p. 13). Black women have contributed to the rising rates of HIV/AIDS due to many internal and external social factors affecting them across the nation, specifically in the south. Despite having more than 25 years of accumulated research detailing behavioral interventions that can curb HIV risks among women, few U.S. based studies have focused exclusively on Black women and only a limited number of studies focused on this population for the CDC sanctioned evidence-based HIV prevention (Caldeira, El-Bassel, Gilbert, & Ruglass, 2009). Furthermore, little research has been conducted to show how issues such as demographic and policy concerns affect the sexual behaviors of Black women and how to overcome those barriers.

In the literature review, current research on demographic disparities and policy issues and how those variables affect the rising rates of HIV/AIDS among Black women in the south were reviewed. The relevant studies included the main themes of class, race, gender, location, and sexual orientation as well as policy issues such as government reinforced stigmas within healthcare. The literature review covered the social learning theory along with discussing demographic disparities and government enforced stigmas as discussed in chapter 1.

Literature Search Strategy

The Walden University Library was used to search for the literature within this review. Academic Search Complete and ProQuest was used because it covers numerous disciplines of study. *HIV, AIDS, Black women, stigma, discrimination*, and *south* were some of the search terms used. The literature was limited to the years 2009 to 2015. Literature for the social learning theory did not have a date range.

Social Learning Theory

Albert Bandura's social learning theory (1977) focuses on a concept that individuals learn from each other via observation, imitation, and modeling. This theory has been looked at as being a bridge between behaviorist and cognitive learning theories because it encompasses memory, attention, and motivation (Bandura, 1977). One element of the theory is that people learn by watching others. Bandura explored the concept that an environment causes certain behaviors to arise and behavior causes environmental factors to grow (1977).

Bandura (1977) states that the basic social learning concept consists of observational learning composed of "watching" and "seeing" the manifestation of behaviors. In 1961, Bandura conducted a controversial experiment called the bobo doll to show patterns of behavior as it relates to aggression. The bobo doll was an egg-shaped balloon with a weight in the bottom that made it pop back up when it was knocked down. This experiment involved showing kindergarten children a film of a woman beating up a bobo doll. During recess time, the kindergarteners played with a new bobo doll and mimicked a lady in the film. This experiment showcased the observational aspect of learned behaviors. Also, mental states such as pride, satisfaction, and a sense of accomplishment help to connect learning theories to cognitive learning theories (Bandura, 1977).

Another step of the social learning theory is the modeling process. This process consists of attention, retention, and reproduction and motivation (Bandura, 1977). In order to learn something, a person has to pay attention. Certain factors such as sleepiness will reduce attention span. Retention involves remembering what a person paid attention to and being able to pull up the stored information and duplicate that behavior (Bandura, 1977). Reproducing an image is an example of reproduction, and a person can have the desire to emulate certain behaviors through motivation (Bandura, 1977).

Within this study, the concepts of demographics and policy were reviewed as they relate to the behaviors of the participants based upon certain learned and emulated traits. This included any observational traits gained because of HIV/AIDS-related stigmas, discrimination, fear, and rejection. The interviews conducted consisted of observing certain behaviors and determining what type(s) of observational and modeling behaviors may have been learned through watching, listening, or hearing others regarding demographics and policy issues.

Demographic Disparities

Class

Sharpe, et al. (2012) examined how issues of poverty, loss of status, and lack of emotional support are comingled with the decrease in marriage participation and single-parent households, all of which impact increases in sexual risks. U.S. Census Bureau statistics state that nearly one in four Blacks are living in poverty and that a large gap in income levels exists for Black women when compared to other ethnicities (Cdc.org, 2015). The vulnerabilities of living in poverty create an environment where many citizens communicate less with healthcare providers, reducing their access to medical screening (Sharpe et al., 2012).

Marriage rates for Black women have declined greatly over the past few decades due, in part, to decreased partner options, shifting the gender power of many women (Sharpe et al., 2012). This difficulty has created less room for negotiation of condom use and self-protection. Sharpe et al. (2012) stated that circumstances of poverty and non-education compel Black women to depend heavily on their men partners, creating an environment that uses sex as a survival mechanism.

Based upon U.S. statistics, HIV/AIDS is more prevalent among ethnic minority communities and mortality rates are the highest among Black women between the ages of 25-34 (Lopez, Antoni, Fekete, & Penedo, 2010). Black women living with HIV in low-income areas may have a psychosocial disadvantage because they may feel the pressure of stressful experiences due to a chronic debilitating illness, minority status, and low socioeconomic status (Lopez, Antoni, Fekete, & Penedo, 2010). Many theories suggest that having a strong sense of ethnic identity can possibly offer a specific advantage over minority group members with less of a sense of ethnic identity due to their feelings of being accepted by society (Lopez, Antoni, Fekete, & Penedo, 2010). This does not negate the fact that minority groups continue to face major hurdles because many demographic variables prevent them from having adequate social supports.

Race and Gender

Women experience HIV related stigma due to an increased susceptibility to HIV infections. In addition, social differences and gender disparities present prevention challenges, including negotiating condom use or asking about high-risk behaviors (Florom-Smith & DeSantis, 2012). The basic conceptual model of HIV risk is that there is not one major predictor of women's HIV risk but that demographics, sexual history, interpersonal negative experiences, and attitudes towards sex are important to the assertiveness that Black women may display (Kennedy & Jenkins, 2011, p. 143).

Sutton, et. al. (2009) studied the growing disparity of HIV/AIDS among Blacks and Whites and the impact that the disease has had on minorities over the past few years specifically among Black women. The CDC conducted data gathering on how HIV/AIDS has disproportionately affected Blacks and Hispanics over the past few decades.

The CDC has stated that other sexually transmitted diseases, such as gonorrhea and chlamydia, have increased the risk of HIV infections, and in order to address the issue and stop the spread of the disease, there needs to be increased screening and treatment methods (Cdc.org, 2015). Over the past few years, the CDC has implemented various programs to respond to the growing transmission of HIV/AIDS among Blacks, but these programs have not fully addressed issues this population is currently facing.

Kennedy and Jenkins (2011) found that having unprotected sex with a man is the most common way that Black women are contracting HIV/AIDS. Kennedy and Jenkins (2011) concluded that sexually active women must assert themselves when communicating information about preventing sexually transmitted diseases. Kennedy and

Jenkins (2011) also point out that there are many issues that affect the increase of HIV/AIDS among Black women, which include interpersonal behaviors such as low self-esteem.

Kennedy and Jenkins (2011) also uncovered that the pattern of risky behavior is actually attributed to emotional, financial, and physical stress, as well as coping mechanisms, which lead to certain behavior patterns. The article reveals that some Black women have gone through many life circumstances that create an inability to focus on positive health choices.

Kennedy and Jenkins (2011) looked at the role that sexual assertiveness plays in how Black women are able to protect themselves from HIV/AIDS as well as some of the indicators associated with their behaviors. Behaviors that remain concerns are sexual self-esteem and control over negotiating issues such as condom use with sexual partners. All of these relate to understanding how to assess and characterize Black women's sexual assertiveness and the vital role it plays in reducing the spread of HIV/AIDS.

One of the major barriers to preventing the spread of HIV/AIDS among Black women is communication. Kennedy and Jenkins (2011) describe how indirect communication was established during slavery because direct communication was prohibited, which means that exposing sensitive information contradicts the cultural values that Black people have been taught. Payton, Kvasny, and Kiwanuka-Tondo (2013) discuss how communication with physicians can be problematic because prior studies have found that health provider bias, stereotyping, clinical uncertainty, and prejudice can possibly contribute to disparities in care along the lines of gender, class, race, and ethnicity. Black women have to overcome their fear of communication in order to gain sexual control over their health. It is important to discover the right types of sexual negotiation skills that can be implemented and integrated into HIV awareness and prevention strategies for Black women.

Location

Vyavaharkar et al. (2011) studied the behaviors and relationships between HIV disclosure, social support, and depression among Black women with HIV/AIDs living in the rural south (p. 78). This study explored how Black women living in the south are often under-diagnosed and not adequately treated for issues like depression. There is a lack of understanding of the role that social support and HIV disclosure play, specifically for Black women living with the disease in the southeastern United States (Vyavaharkar, et. al, 2011, p. 79). Lack of social support stems from judgmental and unsupportive people or relationships leads Black women to withdraw from conversations about the disease, resulting in social isolation, which can lead to a faster progression of the disease and a poorer quality of life (Vyavaharkar, 2011). Poverty status and healthcare coverage is limited in many rural areas in the south, which in turn, aids the rising rates of HIV in this area.

Lloyd et.al (2012) studied factors such as public schools' sex education policies and practices as major barriers towards preventing HIV infections in the south. The south is considered the "bible belt" of the nation, an area of the U.S. mainly in the south and midwest, which is labeled for its religious fundamentalism (Merriam-webster.com, 2015). Within the bible belt, many residents have very strict opinions on premarital sex as well as other stigmas that impact sexual choices and decisions. Participants of the current study disagreed with many of the policies surrounding the issues of abstinence and premarital sex as indirectly enforced by southern states. They felt that a lack of comprehensive sexual education programs in the school system was a contributing factor to the high HIV/AIDS rates among Blacks. The study concluded that not only was there strong support for improving sexual health education and increasing access to health services and condoms in schools, but participants also felt these interventions would help to reduce the spread of the disease. Overall, participants agreed that things would not change unless certain stigmas and discriminatory practices were eliminated.

AIDS is the third leading cause of death among Black women between the ages of 35 and 44 years old, and Black women are generally 15 times more likely than White women to be infected with HIV (Pillay, 2011). The epidemiological pattern of HIV/AIDS in Black communities in the deep south (Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina) has a similar resemblance to countries that have a fraction of the healthcare budget of the U.S. With areas in the south (in one of the richest countries in the world) having an identical footprint to underdeveloped countries, there are two main issues. First, there is something unique between the interplay of HIV and the Black population. Second, prevention and treatment plans that are successful for other racial groups in the U.S. may not always be as successful for Blacks.

Sexual Orientation

MSM's are at the greatest risk of acquiring HIV, specifically because this group comprises nearly half of the total HIV cases (Florom-Smith & De Santis, 2012). HIV surveillance data reveals that approximately 18% of people infected with HIV are unaware of their infection, with Black Americans less likely to know their HIV status than Whites (19% vs. 15%). In addition, MSM studies indicate that MSMs belonging to minority ethnic groups are less likely to know their HIV status (44% vs. 54%) and in turn, may be more likely to transmit HIV to their sexual partners unknowingly (Bird & Viosin, 2013).

Based on the high percentage of people who are unaware of their diagnosis, prevention strategies have shifted toward routine HIV testing, and many perceive that HIV has become less stigmatized. However, there are still challenges that arise due to negative perceptions of those infected with HIV. Recent findings indicate that Black MSMs were less likely than their White counterparts to divulge their HIV status to their sexual partners. This may be attributed to the community-based stigma (e.g., churches) regarding homosexuality that has a significant impact on HIV disclosure.

Saleh et al. (2011) study focused on understanding the beliefs about MSMs and their professional values. Three themes arose from data: critical attitudes toward MSMs, consequences of the increased focus on MSMs, and barriers to open dialogue among MSMs clients. Women service providers mentioned that the Black community often has negative attitudes towards MSMs and that they perceive them as “selfish” and “sneaky”. Empathy was expressed for the women partners of MSMs, with women service providers perceiving that the risks posed to Black women were attributed to the behaviors of Black MSMs. Many of the men respondents discussed the isolation and internal conflict that Black MSMs may experience due to cultural stigma and shame. Men service providers mentioned that they experienced challenges providing HIV prevention services to MSMs because of MSMs inability to disconnect certain cultural beliefs about masculinity and sexuality.

HIV/AIDS Policy in the U.S.

Governmental and Health Issues

Prior research on government enforced stigmas, has shown that stigma plays a role in racial ethnic health disparities, but there is limited research that focuses on understanding the mechanisms of how stigma contributes to HIV-related disparities in risk, incidence, screening and treatment, or what can be done to reduce the stigma based upon these disparities (Earnshaw, Bogart, Dovidio, & Williams, 2013). HIV disproportionately affects those Americans who have less access to prevention and treatment services, and the reduction of stigmas is a critical step towards decreasing health and HIV disparities. Disparities in healthcare are often associated with higher mortality rates among minority groups (Horton, 2010). The stigma and HIV disparities model listed in figure 2 showcases the relationship between societal stigma and racial/ethnic HIV disparities.

Historical antecedents continue to affect the Black community's distrust of the medical establishment (Pillay, 2011). Examples of this distrust include both recent events, like Hurricane Katrina, as well as historical events like the Tuskegee Syphilis Study, which used unethical methods of withholding treatment from Black men who tested positive for syphilis. The HIV costs and services utilization survey suggests that the race of physicians also impacts treatment regimen. Additionally, the HIV costs and services utilization survey suggests that Black patients who do not trust the prescriptions given to them by White physicians tend to delay highly active antiretroviral therapy (HAART) (Pillay, 2011). Researchers have found that Black patients have the attitude that White mental health professionals are racially biased agents with solutions that may not be consistent with their patient's cultural values (Pillay, 2011).

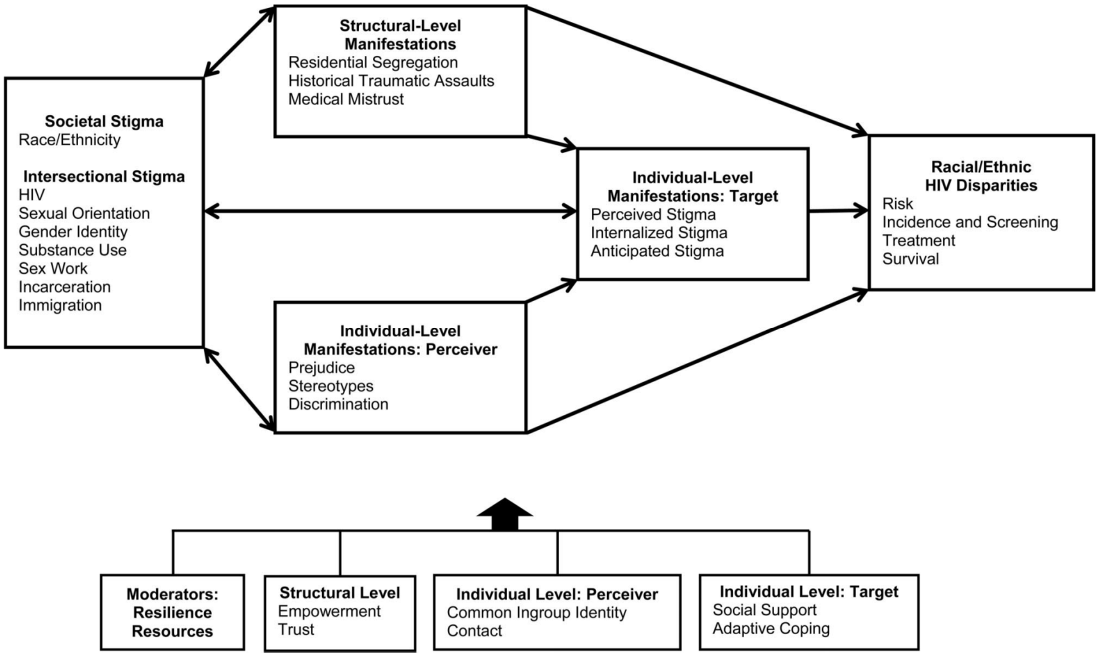

Figure 2. stigma and HIV disparities model. Adapted from "Stigma and racial/ethnic HIV disparities: moving toward resilience," by V.A. Earnshaw, L.M. Bogart, and D.R. Williams, 2013, *American Psychology, 68, p. 225-36.*

Grossman, Purcell, Rotheram-Borus, and Veniegas (2013) found that, despite advances in HIV prevention and care, Blacks and Latin Americans have a much higher risk of acquiring HIV and are more than likely to be unaware of their HIV status and less likely to be connected to healthcare. One of the three goals of the first national HIV/AIDS strategy (NHAS) is to reduce disparities by encouraging the implementation of high-impact HIV intervention strategies (Grossman, Purcell, Rotheram-Borus, & Veniegas, 2013). Unfortunately, health disparities exist at every level of the HIV care continuum. In order to further reduce health disparities, successful implementation of NHAS and prevention strategies will require the use of psychologists and behavioral scientists with diverse backgrounds and experiences to engage high-risk HIV groups.

Summary

The current literature explores the issues of poverty, marriage rates, MSM, location, stigma, and discrimination as a few of the variables affecting the growing epidemic of HIV/AIDS among Black women. Many Black women in the south are faced with barriers such as elimination of sexual education programs in schools, closing of health facilities, and lack of access to health insurance. The HIV prevalence rate for Black women is 1122.4 infected per 100,000 women, almost 18 times the rate for White women (Chen, Meyer, & Springer, 2011). Black women have become vulnerable to the disease, primarily due to heterosexual contact with sexual partners from the neighborhoods in which they live, which can be impoverished.

Much of the stigma and discrimination towards the disease stems from government enforced stigmas, especially within healthcare facilities (i.e., testing centers). With the south holding many specific beliefs regarding sex and sexual orientation, fear of being ostracized is prevalent in ethnic communities. The literature discussed many demographic and policy issues around HIV/AIDS, but there is a gap in explaining how the two variables work in partnership to inform certain sexual decisions Black women make that result in spread of HIV/AIDS.

Chapter 3 describes the methodology for this study, which explores the overall themes and concepts derived from the gathered research.

Chapter 3: Methodology

This qualitative study adopts a phenomenological approach to understand how Black women in the south understand their sexual health in the age of HIV/AIDS. Phenomenology is the study of lived experiences from a first person point of view (Stanford Encyclopedia of Philosophy, 2015) Utilizing the social learning theory of modeled and observed behaviors among Black women as it relates to HIV/AIDS and their lived experiences helps to provide a the backdrop of this phenomenological study. Providing in depth understanding of human behavior and its connection with sexual health decision making and related behaviors is important in understanding the sexual choices made by Black women. Semi-structured, open-ended, in-depth interviews were developed to assess a wide range of HIV-related topics with an emphasis on demographic disparities and institutional stigma.

A general population of Black women ages 24-35, regardless of HIV status, as well as healthcare workers in Georgia were interviewed in person. The southern HIV/AIDS strategy initiative (SASI) found that over the four-year period of 2008-2011, the deep south region (Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Texas) had the highest rates of HIV and AIDS diagnosis and case fatality rates for each year during this time period (Southern HIV/AIDS Strategy Initiative, 2012). Georgia has the fifth highest numbers of HIV/AIDS cases compared to the other deep southern states. Recruitment was conducted at HIV testing facilities in Georgia. Participant observations were conducted as another means to understand participants' experiences. The researcher spent eight hours on two separate days in a clinical setting at two community partner locations.

Research Design

The present study investigates the sexual health experiences of Black women ages 24-35 living in Georgia, a group that is highly susceptible to HIV/AIDS infection. A phenomenological design was selected because it allows the researcher to describe the lived experiences informing these women's sexual health. . Phenomenology focuses on participants' subjective experiences and their interpretations of the surrounding environment, providing a lens through which we may better understand people's worldviews (Creswell, 2009).

Drawing upon in-depth interviews with both HIV testing coordinators and administrators and Black women clients, as well as observations of both within the testing facility, the study seeks to answer the following research questions: What are the shared experiences of sexual health among Black women in Georgia? How do Black women in Georgia make sense of their sexual health decision making and behaviors within the shifting healthcare climate? and In what ways do stigma and discrimination inform these women's sexual lives given the climate of HIV/AIDS in the south?

Setting and Sample

The target populations for this sample were Black women clients ages 24-35 years old and HIV testing coordinators and administrators over the age of 18 in Georgia. The southern AIDS coalition (SAC) states that southern states make up 37% of the U.S. population but represent 50% of new HIV infections in the U.S.

(Southernaidscoalition.org, 2015). A convenience sample was taken from HIV testing coordinators and administrators who are employees of the HIV/STD testing facility and Black women clients who are HIV positive or negative. HIV testing coordinators and administrators were chosen because they are the first point of contact when Black women are coming to their locations with issues or questions regarding their sexual health. HIV testing coordinators and administrators have the knowledge and experience to provide guidance regarding HIV/AIDS and to discuss the issues they are seeing within the Black community.

The healthcare workers were selected based on employment at the facility as well as their access to clients to discuss health related issues. Black women clients were chosen based upon their ability to provide shared experiences on the sexual decisions that they are making day to day along with behaviors that they may be modeling. Black women participants were selected based on the following criteria: Black women ages 24-35 years old (self-identified) and they were associated as clients to the health facility. There is an overlap in Black women HIV testing coordinators and administrators and Black women clients within this study due to population statistics. Based upon the 2010 Census, the racial makeup of Atlanta was 54 % Black. Due to these statistics, the probability of the testing centers having majority Black HIV testing coordinators and administrators was realized.

The community partners who were a part of this study included Fulfilled Destiny and One Love, both of whom are located in the Atlanta, GA metropolitan area. Fulfilled Destiny, Inc. is a non-profit organization focused on women's HIV/AIDS and reproductive assistance, specifically for those of Black descent. Fulfilled Destiny was founded in 1989 as a volunteer group of women interested in educating women in Atlanta, about HIV prevention. One Love is a non-profit focused on health disparities among Black people, mainly the overwhelming sexual issues of Black, gay men. One Love was created in 1990 to counteract the increasing spread of HIV/AIDS in communities of color. Both community partners allowed research to be gathered within their facilities with an open agreement for participating in this study. The organizations were chosen based up their existing HIV testing programs and their physical location within the city of Atlanta. Select dates were chosen for data to be collected based upon communication between both organizations and in person interviews were conducted on confirmed dates and times.

This study gathered participants from two different sectors: One set of participants that included Black women ages 24-35 and another that included healthcare workers (including Black women) of any race over the age of 18. Convenience sampling was used to select participants. This study included both men and women participants from African-American, White, and Hispanic descent. Both sets of participants were recruited in the state of Georgia within the metropolitan area of Atlanta. Over 98% of the total participants were Black, 1% White, and 1% Hispanic.

Sample Size

In a phenomenological research study, human science recommends working with at least three participants (Englander, 2012). The purpose of this approach is not to see *how many* have had similar experiences, but rather, *how many* times the phenomenon makes its presence known (Englander, 2012). Many qualitative studies involve 5 to 25 participants who are able to give in-depth descriptions of the phenomena being addressed (Creswell, 2009). Based on matters of geographical location, travel, and time, it was feasible to use a maximum sample size of 30 individuals (15 Black women clients and 15 HIV testing coordinators and administrators).

Recruitment, Participation, and Data Collection

Internet research was conducted in order to identify facilities in the metropolitan Atlanta area that focused on HIV testing, sexual health education, and counseling. After receiving IRB approval 09-03-14-0263337 in September 2014, Fulfilled Destiny and One Love were selected based upon review of their website and contacted by phone to request their participation in this study. Both HIV testing facilities were emailed a letter detailing the purpose of the study and asking for permission to conduct the research at their site (appendix d). After sending an email in October 2014, Fulfilled Destiny and One Love responded back with their consent to conduct research at their facility. A date and time were scheduled in early November 2014 with both facilities to conduct the research once permission was granted. A flyer was emailed to the facilities to post in an open forum so that the public was aware of the study. The flyer contained information regarding the nature of the study, the date the research was to be conducted, and the confidentiality of potential participants' personal information. On the date that the research was to be conducted, all of those who agreed to participate were provided with an informed consent form. The participants had an in-depth interview based on their behaviors and experiences. Copies of the interview guides are listed in Appendix A and B, respectively. Participants who were interested in the results of the study were provided those results via email. Participants provided their email address(es) on the consent form.

Methods

There were two dates chosen for both participant locations, Fulfilled Destiny and One Love, based upon discussions with management. Both organizations were called and after discussion with the decision makers, an email of the specifications of the study, along with the IRB approval form was sent out. Initially 30 participants were sought, but due to the limited staff and number of walk-ins, 21 total participants were used (12 in the healthcare official's category and nine in the category of Black women clients). Upon arrival to the organizations that were partnered for research, a Walden IRB approved consent form and HIPAA information sheet were given to each participant at various times. The consent forms described data collection process along with other pertinent information regarding the research study as a whole. The participants were aware that at any time they could discontinue the interview process and that their participation was strictly voluntary. The participants were not provided with any incentives for completing the interview process.

At Fulfilled Destiny, three offices were used to collect data with the participants at various stations. One Love allowed researched to be collected in a conference room setting. At both locations a cell phone was used to collect audio throughout the interview process and instructions were given for each interview. At Fulfilled Destiny, six HIV testing coordinators and administrators and four Black women clients were interviewed and at One Love six HIV testing coordinators and administrators and five Black women clients were interviewed. The participants were interviewed individually and during the process, questions were asked and then written down on a sheet of paper. If a question was not understood, it was stated again for further clarification. After the interviews, the answered research questions were stored in a lock-protected binder and the audio memos on a password protected cellular phone. This section provides the specific data collections methods.

This study used open coding to analyze data collected. Open coding consists of specific concepts and categories in data, which form the basis of the analysis of the research study (Qualitative Coding & Analysis, 2015). The reason this method was utilized is because it helps in interpreting the raw data collected and reflected upon the various perspectives and themes that derived from research. All 21 interviews were conducted utilizing standardized, open-ended questions and each participant was asked the same pre-constructed set of statements. The participants were divided into two sections: HIV testing coordinators and administrators or Black women clients. Based upon the section that the participant fell in, they were asked questions from the Interview Guide A or Interview Guide B list (appendix a and b). Black women clients were asked 19 questions from the interview a list and HIV testing coordinators and administrators were asked 23 questions from the interview b list.

In-Depth Interviews

The research questions were developed and conducted independently by the researcher. At both locations, the interviews were audio recorded through the audio memo application on an iPhone. The responses and observations were also typed up in a Microsoft Word. All data collected were on password-protected devices. The researcher utilized various rooms at both locations based upon the direction of the participants and being able to shadow them through an eight-hour time frame. Participants were initially asked if they would participate and a description of the study was delivered to them verbally. Once the participants agreed, they were given a consent form and then the process of recording their answers began. All of the interviews were conducted individually but observations were done with or without the presence of other parties involved at the health facility. Once the interviews and observations were done for the day, the researcher informed the facility that a follow up email would be sent regarding the study. An email was then sent a day later, thanking the community partners for their time and to let them know that any questions or follow up that they may have would be answered by phone or email.

In-Depth Interview Guide A.

Interview guide a was developed to gather demographic data such as age, education level, sexual orientation, and income among Black women (appendix a). Black women clients were asked questions under this guide. The first set of questions on interview guide a fell under the umbrella of demographics and asked about age, level of education, household income, and marital status. The next set of questions asked participants about their background and views on demographic variables as it relates to Black women and HIV/AIDS. The third set of questions asked the participants about sexual-decision making, sexual orientation, and HIV status. The fourth set of questions asked about perceptions and discrimination of HIV/AIDS. The fifth set of questions asks about the ACA and healthcare related issues and concerns. The last set of questions asked about education programs and healthcare facilities roles in reducing HIV/AIDS.

In-Depth Interview Guide B.

Interview guide b explores programmatically actionable drivers of HIV-related stigma and discrimination among healthcare facility staff. (appendix b). HIV testing coordinators and administrators were asked questions under this guide. Interview guide b's first set of questions asked about age, race, current job and title, and how long he/she had been working in the healthcare field. The second set of questions asked about HIV testing/care and the ACA. The third set of questions asks about behaviors, discrimination, and health concerns. The fourth set of questions asks about demographic variables, social concerns, and disparities. The last set of questions asks about program elimination, distrust, and accessing medical care.

Observations

All of the participants were observed during an eight-hour time frame at the facilities that were chosen. This consisted of being able to follow both the Black women clients and HIV testing coordinators and administrators around during their time frame at the facility. During the observation, the researcher was able to see HIV testing from point a to point b up to and including counseling, support for those who had already been diagnosed with HIV, along with following the job duties and responsibilities of the HIV testing coordinators and administrators. These observations consisted of taking notes and recording audio memos that would later be transcribed.

Evidence of Trustworthiness

Each interview was audio recorded using a recorder application on an iPhone along with handwritten notes taken on paper. The recordings were then copied to a secured hard drive and then deleted from the iPhone. A dragon dictation application was used to ensure that the interviews were transcribed verbatim. The interview notes were typed up using Microsoft Word on a secured hard drive and then the original documents were shredded.

Providing participants with a copy of their transcript and interview notes to review it for accuracy completed member checking. The copy of the transcript and interview notes was stored on a password -protected computer. It was difficult to get a return receipt from each participant, but eventually everyone returned it and it was verified by phone and email. Each participant was pleased with the results.

Continuous efforts were made to avoid any possible threats to validity by avoiding any leading questions and keeping only professional, limited contact with the participants. Each participant’s responses were recorded as spoken and were careful not to insert bias on the research results. Each participant was treated fairly and with respect regardless of background or medical status.

Data Analysis

Handwritten and audio memos were used to collect data for the study. A transcription software was used to convert human speech into a text transcript. The initial audio memos were recorded on a password-protected iPhone, which provided an application for collecting the audio. The transcription along with handwritten notes from the interview was then used to start the open coding process, which was the first method in the data analysis process. Grouping certain labels to words or phrases created themes and/or categories among the data collected. Finding a relationship between the codes allowed emergent themes to be identified. An example of the types of coding that was used in this study is listed in Table 1.

Table 1.

NO.	WHAT CAN BE CODED	EXAMPLES
1	Behaviors, specific acts	Seeking reassurance, Bragging
2	Events – short once in a lifetime events or things people have done that are often told as a story.	Wedding day, day moved out of home for university, starting first job
3	Activities – these are of a longer duration, involve other people within a particular setting	Going clubbing, attending a night course, conservation work
4	Strategies, practice or tactics	Being nasty to get dumped, Staying late at work to get promotion
5	States – general conditions experienced by people or found in organizations	Hopelessness "I'll never meet anyone better at my age" settling for someone who is not really suitable
6	Meanings – A wide range of phenomena at the core of much qualitative analysis. Meanings and interpretations are important part of what directs participant's actions.	
	a. What concepts do participants use to understand their world? What norms, values, and rules guide their actions	The term 'chilling out' is used by young people to mean relaxing and not doing very much
	b. What meaning or significance it has for participants, how do they construe events what are the feelings	Jealousy " I just felt why did she get him"
	c. What symbols do people use to understand their situation? What names do they use for objects, events, persons, roles, setting and equipment?	A PhD is referred to as 'a test of endurance' (because finishing a PhD is a challenge)
7	Participation – adaptation to a new setting or involvement	About new neighbors "In my new house I have to keep my music down at night as the neighbors have young children".
8	Relationships or interaction	Seeing family "Now my sister lives in the next road she visits more and we've become much closer.
9	Conditions or constraints	Lose of job (before financial difficulties), moving away (before lost contact with old friends)
10	Consequences	Confidence gets dates, positive attitude attracts opportunities
11	Settings – the entire context of the events under study	University, work place, housing estate
12	Reflexive – researcher's role in the process, how intervention generated data	Probing question "How did you feel when he said that?"

Note. Types of phenomena that can be coded (Adapted from Bogdan and Biklen, 1992; Strauss, 1987; Mason, 1996; and Gibbs, 2006). Reprinted with permission.

Interview transcripts were read and then common words were highlighted. Coding and recoding were conducted and the transcripts were reviewed again. Common words and phrases were coded and the first and second reading of the coded words and phrases were then compared. Categories were then created based upon the participant's words and theories were then created as it relates to the phenomena uncovered and topic (as shown in Figure 3).

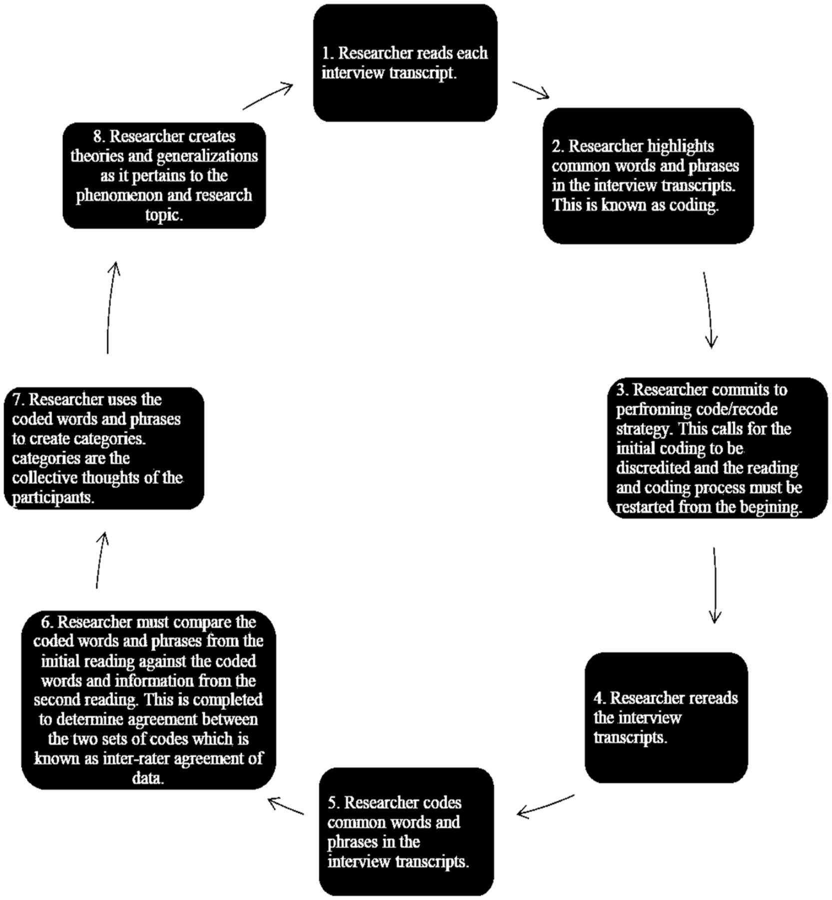

Figure 3. steps of data analysis procedure. Reprinted from Information Qualitative interpretative categorization for efficient data analysis in a mixed methods information behavior study, In Information Research, n.d., Retrieved September 14, 2015 from http://libguides.gwumc.edu/c.php?g=27779&p=170358 Copyright 2013 by Peter Stokes. Reprinted with Permission.

Ethical Considerations

Permission was requested from the head officials at the HIV testing facilities in order to recruit participants from their facilities. A letter was sent to administration requesting permission to conduct the study. Confidentiality of responses was stated in the letters and flyers that were sent and given directly to the facilities. In addition, confidentiality was reiterated when participants started the interview process. Confidentiality was listed on the informed consent form. The informed consent form included details regarding the study, nature and purpose of the research, and contact information. Participants' personal information was not listed on any of the interview questions or interview information in order to ensure confidentiality. Participants were able to send an email to the contact information listed on the consent form if they wanted a summary of the findings.

Data received from the participants was stored on the hard drive of a password-protected computer. A password-protected USB drive was used to back up data. Any physical paper data was shredded once the research was completed. Data on the hard drive and USB drive will be stored for a maximum of five years, and then it will be destroyed.

Threats to Validity

Based upon this particular study of HIV/AIDS and the questions surrounding the disease, there were some threats to validity. Creswell (2009) states that threats to internal validity occur based on treatment, experiment procedures, and participants' experiences. One threat to internal validity was participant bias. This study used convenience sampling of gathering participants and not a randomization of selection. There were some biases from the participants based on their views on HIV/AIDS and minority groups. Making sure that selection bias was noted within the study helped to ensure that the analysis and discussion of the results were valid. Inaccurate generalizations by the researcher can create external validity threats within a study (Creswell, 2009). The participants within the study consisted of Black women clients ages 24-35 as well as HIV testing coordinators and administrators at facilities in Georgia. The results from this study can, hopefully, lead to a reduction both in the demographic disparities and stigmas associated with HIV/AIDS as well as the rise of rates among Black women in the south. Although the study was related to Black women, it was not generalized to just one ethnic group, but also included women and men of other races in their roles as client-facing employees at healthcare facilities.

Summary

The research was conducted using a qualitative, phenomenological approach to understanding the demographic disparities and policy issues affecting the rates of HIV/AIDS among Black women in Georgia. A sample of Black women, ages 24 to 35, and HIV testing coordinators and administrators, age 18 and over, in Georgia were selected from HIV testing facilities. In-depth in-person interviews were conducted utilizing primarily open-ended questions and observation techniques. Coding was used to identify themes and showcase the behaviors that were observed based on the foundation of the social learning theory. The confidentiality of the participants was protected along with data collected. After five years, data will be destroyed. Chapter 4 describes a review of data that was collected.

Chapter 4: Findings

Introduction

The purpose of this phenomenological study was to understand the sexual health decision making and behaviors of Black women in the south. The lived experiences of nine Black women and twelve HIV testing coordinators and administrators was supported by six hierarchal themes: a) Lack of education, b) Limited access to healthcare, c) Sexual health choices d) Stigma/discrimination, e) Provider empathy and awareness, and f) Community distrust.

The first section of this chapter gives a brief introduction of all of the participants. I developed the descriptions of the participants using components of the secondary data found in appendix c. The participants are introduced in alphabetical order and the patterns and themes based upon their responses are discussed throughout.

Participants

Black Women Clients

Alice.

Alice is a 28 year old married woman with two children. She comes from a family of two siblings and was raised in the south. She married at the early age of 19 and became sexually promiscuous at the age of 14. She had her first child at 16 and then her second child after being married. During her early years of sexual activity she did not use protection and was not aware of birth control or STDs. She has several family members who had children when they were teenagers and she mimicked the behaviors that she saw growing up. Alice was not around any discussion of sex as an adolescent and grew up not making the safest sexual choices. She knew it was considered taboo to bring sex up as a topic of conversation. Alice believes that she was not educated as she needed to be and admits to having a sexually transmitted disease before marriage. Now that she is married she does not use protection but admits to her husband having committed adultery in the past and trust issues are of concern to her, especially with regard to STDs..

Beatrice.

Beatrice is a 32-year-old woman who is single. She discussed that she never wants to get married or have children. She makes $35,000 per year and has ambitions to make more after she furthers her education beyond the high school level. She believes that the issue of HIV/AIDS has a direct correlation to income and education. Beatrice has acquired an STD in a past relationship. At this point, she is not in a relationship and is scared to date anyone based on all the current diseases that are continuing to spread within the community. Beatrice believes that Atlanta is full of many women who are vying for the same man and she does not have the energy to compete with other women. She has seen a lot of men in and out of her mother's life and it was a source of discontent as she got older and felt as if her mother was choosing men over her own daughter. Beatrice only recently found out about the testing facility she is currently visiting and wants to get tested based upon a relationship that she recently ended.

Carol.

Carol is a 34-year-old woman who is divorced with one child. She has her juris doctorate and makes over $150,000 per year. It has been hard over the past few years for her to maintain a successful relationship, but she has currently been in a relationship for a year. Carol discusses that they do not currently use protection and although she feels that she is in a monogamous relationship, she is not 100% sure that her partner is faithful. She understands that she needs to get tested now and be aware of her sexual health. In her marriage she gave all the control to her husband and during her marriage, she dealt with domestic violence that has affected her ability to trust in future relationships. After five years of marriage she was able to leave and only within the past two years has she started dating. Carol has dealt with stigmas going to see a healthcare official. She feels as if she has been received as being “uneducated” before health professional actually knows her background due to her race. Once a healthcare official finds out her education level, their rapport towards her changes into more compassion and empathy.

Elise.

Elise is a 27-year-old woman who is divorced but newly engaged to be remarried. She has three children and struggles financially because of an income of $500 a month. She admits to having received an STD from her current fiancé who was released from prison after three years. She also admits that when she was 12 years old, a family member sexually assaulted her and that no one believed her when she spoke up about the incident. It was a daunting experience that left her emotionally troubled and she admits to current violence at times in her relationship but that she will not leave because she loves him. Elise has three sons and does not want her children to continue to grow up seeing violence. Elise discusses that when her fiancé is at home he takes care of the children but continues to have a violent demeanor at times.

Heather.

Heather is a 25-year-old single woman who has two children. She was recently diagnosed with HIV and is coming into the health facility regularly to receive guidance and support. She admits that she was sexually promiscuous in the past and did not protect herself against STDs. After the birth of her second child, she started dating a guy who was a carrier for the AIDS virus. She realized after several months of dating that her boyfriend was having sex with other men and immediately went to get tested. After learning her diagnosis, she wanted to commit suicide and turned to family and church for moral support to get her back on track with life. If it had not been for her children and the support group at the testing facility, she admits, she would not be alive today.

Monica.

Monica is a 30-year-old single woman with no children. She is a lesbian and has been with men in the past but feels more comfortable with women. She is currently in a relationship with a woman and promised her partner that she would get tested. She grew up in the rural south where her family was deeply religious and spoke out vehemently against homosexuality. She kept her sexuality a secret until she was caught in a sexual act by an aunt who then told her parents. Monica’s immediate family disowned her and she moved to Atlanta and was welcomed by the gay community. She admits that she only found out about the facility after doing searches on the Internet and that there is not much advertisement about free clinics.

Rochelle.

Rochelle is a 35-year-old single woman who is Monica’s partner. They have been together for three months. Rochelle has one child from a previous heterosexual relationship and has always known she was gay, but did not act on her feelings until she was 30. She has dealt with discrimination being a lesbian. This has included her being called out in her former church for being a lesbian, and automatic assumption from healthcare providers that she has or has had sexually transmitted diseases. Rochelle admits that it has been a humiliating experience for her and she personally understands the lack of trust from the Black community regarding HIV testing coordinators and administrators. She is mainly at the testing facility because she agreed to get tested to solidify her relationship status with Monica.

Sheree.

Sheree is a 29-year-old married woman with four children. She admits that she is currently working as a prostitute, the only way she can make money to provide for her family. Sheree discussed that she dealt with her Uncle sexually abusing her while growing up and that led to her promiscuity. She has been in and out of the hospital with sexually transmitted diseases and is currently HIV positive. She does not know whom she contracted the disease from and she is thankful that her children did not contract the disease. She does not have any family support and when she was younger, she ran away from home and never looked back. She moved to Atlanta and got caught up with the a crowd that did not abide by certain laws and eventually became pregnant with twins and then two more children thereafter. She wants to be able to live to see her children grow up but the cost of healthcare and medicine are too expensive. She tries to use free programs but they are limited.

Tanya.

Tanya is a 24-year-old single woman without children. She is focused on her education and is currently pursuing her master's degree. She admits that she has only recently become sexually active remaining a virgin up until a year ago. Her parents taught her to wait until marriage to have sex and did not teach her the concept of sex. Tanya's parents were very strict and she was inexperienced during her first sexual encounter. She eventually contracted an STD and did not know what to do. She spoke with close friends and they referred her to free clinics. Now she has accustomed to getting tested every month even though she is not currently having sex. It has made her scared of having sex again and she does not have the income to pay for medical care or to receive preventive care on a regular basis.

HIV Testing Coordinators and Administrators

Chris.

Chris is a 28-year-old Black man who has been working in healthcare for a year. His role at Fulfilled Destiny is as an HIV prevention specialist. He conducts the testing and gives the results to the clients. Chris discussed that he has a lot of Black women clients who are not educated about their sexual health. Personally, he mentioned that he has encountered many MSMs who are married to women and contracting the disease and then transmitting it to their spouse. Chris admits to being a gay man who has seen the issue of STDs continue to grow within the homosexual community. The main health concerns that Chris hears from Black women clients are issues with lack of transportation (private or public) and costs of healthcare.

Denise.

Denise is a 48-year-old Black woman who has been working in healthcare for over seven years. Her current role at Fulfilled Destiny is as an HIV prevention specialist were she assists with testing, counseling, advocacy, and education. Denise works on research projects and educating others on the role of HIV in the community. Denise discussed economics, accessibility to healthcare, and lack of education as reasons why she believes minorities have the highest incidence of HIV. Denise also mentioned that at Fulfilled Destiny they offer various support programs, which include their Healthy Love program, sexual health literature, brochures, and trainings. Her goal is to treat those who are HIV positive as individuals, with respect and decency. The common topics she hears from Black women clients is that they do not trust the government (i.e., Tuskegee Experiment which focused on the non-treatment of Black men during a government study for syphilis) and that economics, lack of education, and lack of transportation are the main reasons why the south has seen a rise in HIV/AIDS.

Farrah.

Farrah is a 44-year-old White woman who has been working in healthcare for 25 years. She currently works as a health education prevention intern and oversees clients with testing, counseling, and risk reduction. Farrah discussed that the ACA is a step in the right direction because many people do not have access to healthcare. She discussed that the rates are sometimes too high for many of those on the poverty line, specifically in the state of Georgia. Farrah sees a lot of Black women clients who admit that they are engaging in unprotected sex along with having multiple partners. One of the issues that Farrah hears from Black women clients as it relates to distrust is that they believe that doctors are not effective communicators.

Ingrid.

Ingrid is a 30-year-old Black woman who has been working in healthcare for over 10 years. Her current position at Fulfilled Destiny is as an HIV prevention specialist, which consists of performing the actual testing. Ingrid discussed that many minorities do not come and get tested but they also do not have access to health insurance. She also discussed that there seems to be a lot of stigma and discrimination in today’s society and that the general public still looks at HIV/AIDS as a “nasty” disease. Ingrid believes that many people do not understand the virus along with schools not educating children anymore about the disease. She believes that there is a rise of HIV/AIDS among Black women due to MSMs and that sex education is not talked about in the south due to living in the bible belt.

Lisa.

Lisa is a 30-year-old Filipino, Moroccan, and Spanish woman who has been working healthcare for five months. She recently graduated from college and her role at Fulfilled Destiny is law and policy, which consists of working with policy agents, clients, and members to strengthen the resources and to update policy to reflect positive change as it relates to HIV/AIDS. Lisa mentioned that she currently sits in on the testing and counseling for observational purposes works with developing the social support programs at Fulfilled Destiny. Lisa discussed that the ACA has allowed more people to be covered under a plan, but that the Medicaid expansion has left a gap in coverage for Black women. She mentioned that Black women are the second most affected group of HIV/AIDS in Georgia and they are not receiving the medical care they need. She also mentioned that the Black community has distrust among the medical establishment because they believe that they will have better quality of care when dealing with their own ethnic group.

Monet.

Monet is a 56-year-old Black woman who has been working in healthcare for 20 years. She currently works as an HIV prevention specialist at Fulfilled Destiny and oversees HIV testing, works on risk reduction plan, and counseling. Monet discussed that many of the Black women clients that she assists deal with health concerns such as a compromised immune system and dual diagnosis such as hepatitis C and HIV. She also mentions that the Black community does not trust doctors because they feel that they are not doing what they are supposed to be doing as it relates to their health. Her main goal in her position at Fulfilled Destiny is to keep and maintain the confidentiality of her clients.

Patricia.

Patricia is a 52-year-old Black woman who has been working in healthcare for 12 years. Her current role at Fulfilled Destiny is as a bridge leadership program associate which consists of her managing the testing programs, and counseling (pre and post). She described that with the initial introduction of the ACA she thought that it was good but that many clients fail to see the benefits due to copay costs and deciding whether or not they need to feed their child. Many of the health concerns that Patricia hears comes from young Black women who are concerned about being able to have children (due to HIV status) and being convinced by their healthcare provider to have an abortion if they do become pregnant after diagnosis. She encourages her clients to get mental health services once they are diagnosed to help them deal with the HIV/AIDS.

Rachel.

Rachel is a 35-year-old Black woman who has been working in healthcare for over 14 years. Her current role at Fulfilled Destiny is program manager were she oversees client forms, counseling, and risk reduction plans. She discussed that many

Black people have the highest incidence of testing HIV positive due to the "fear of knowing" and they do not like to go to the doctor until they are really sick. Rachel mentions that SES and lack of education are the main demographic variables affecting the rise of HIV/AIDS among Black women in the south. One thing that Rachel pointed out as reasons the south as seen the largest rise of HIV/AIDS cases among Black women, is because the south is transient (a lot of people are not originally from the south, they come from other parts of the U.S.).

Roland.

Roland is a 31-year-old Black man who has been working in healthcare for the past 7 years. His current role at One Love is program manager where he assists with normalizing the experience, creating a sense of urgency with testing, and mobilizing to act as a navigator for clients. Roland mentions that there are so many other pressing priorities for Black women as it relates to their health and unless something major happens, they do not consider it their highest priority. Roland discusses that HIV has stigma associated to its name and in the south, we have a conservative Christian culture were HIV is considered a deviant behavior. Roland admits that he was diagnosed as HIV positive over 6 months ago and even with him working in the field, he did not take the necessary precautions to protect himself believing that he was in a monogamous relationship.

Steve.

Steve is a 24-year-old Black man who has been in healthcare for 3 months. His current role is working as an intern at One Love were he counsels people to help normalize the disease. He discusses that he sees the ACA as too expensive for most people in Georgia and those with a low income can't afford healthcare. Steve believes that many minorities are met with shame or stigma as it relates to HIV/AIDS and that the stress of being a minority leads to lack of prioritizing their health along with the shame of having the positive diagnosis.

Terrell.

Terrell is a 28-year-old Black man who has been working in healthcare for over a year. His role at One love is as an AmeriCorps member were he processes paperwork, guides clients through the testing process, and shows them how to get from point A to B if diagnosed with HIV. He believes that the rates of HIV/AIDS are high among Back women due to lack of education, apathy, and a certain age many young people feel invincible as if nothing will happen to them. Terrell discussed that the ACA was implemented way too fast but it has still helped some people. He believes that the technology structure implemented too quickly and that there are still roadblocks and hurdles to jump over.

Tyrese.

Tyrese is a 26-year-old Black man who has been working in healthcare for over 2 years. His current role at One Love is support services coordinator where he assists with counseling and testing. He mentions that a lot of Black women are dealing with MSMs due to men who are getting out of jail and are not aware of their HIV status. Tyrese discusses that they have discussed stigma and discrimination among healthcare providers with clients and the main concern is that they are receiving fair and equal treatment and getting the proper care needed to live with HIV/AIDS.

Patterns and Themes

Based upon the research questions and data collected, six themes emerged from the research: Lack of education, limited access to healthcare, sexual health choices, stigma/discrimination, provider empathy and awareness, and community distrust. Lower income levels were discussed throughout the interviews as the top-contributing factor that precedes all of the issues that Black women are facing. A majority of the participants suggested that having a low socioeconomic status leads to lack of education and limited or no access to healthcare. Data gathered showcased lack of transportation and the rising costs of the ACA as reasons for the decline of medical coverage and issues with sexual control emerged as a top concern with over half of the participants. This is due to the incarceration of many men and the rise of MSM based upon their relationship status with Black women.

Black Women Clients

Theme 1: Lack of Education.

Two of the Black women interviewed felt that a lack of education due to poverty and those of a lower income bracket had greater chances of contracting HIV/AIDS. Beatrice stated:

> I see that a lot of young Black women who are on the poverty line do not have the education that will help them exceed beyond a lower income bracket. Due to their lack of education, they do not have the knowledge needed to make the right sexual decisions and protect themselves against HIV. I currently have a GED and it has held me back in making more money and connecting with others who will be able to help me excel. I believe that those who do not have a lot of education do not understand the disease and ways that they need to protect themselves.

The concern is that many Black women who do not have a certain level of education are more susceptible to contracting HIV because they are not knowledgeable on facets of HIV and do not have the income that will provide the resources needed to educate them on their sexual health.

Alice stated:

> If you are really poor, you get all these benefits, and there are mechanisms that keep you in that poverty bracket because some entities require you to report certain income and it's designed for you to stay at a low-income level to qualify

> for certain benefits. I see a majority of Black women in Atlanta who are poor have a lack of education, specifically sex education. A lot of the inner city schools in Atlanta do not provide the sex education programs due to defunding by local and state government. I was sexually active at an early age and had my first child as a teenager. I stayed in a subsidized housing project were all the behaviors you saw were sexually promiscuous women. If I had the education, or my mother had the education, we would not have been around those behaviors and would have been able to make more money to live in a better area.

Alice shared that she realizes mistakes she has made in not being educated about her sexual health and her school education. She mentioned that she knows younger, lower income Black women in her community that participated in high-risk sexual activities that has bought them nothing but STDs and heartache. Beatrice stated: "The resources are not available in lower income/urban areas and many Black women are not able to afford the educational services or are not aware of certain low cost services within their area." Both women believe that those in a lower income bracket live in communities did not offer the educational resources they needed to protect against HIV/AIDS. They believe that a lack of funding in their neighborhoods is what leads to the issues of certain sexual risky behaviors being enacted along with many Black women not understanding the disease which leads to them not receiving the medical care that they need. Alice stated: "Many of the urban communities in Atlanta do not have the resources to educate minorities on sexual education and there are many who are living in poverty and can't afford the educational opportunities likes those of affluent status can."

With Georgia being in the "bible belt" of the south, many sexual education programs are not taught in schools/community and the issue of education seems to be a common denominator for all of the issues that are affecting HIV/AIDS among Black women. A few of the participants stated that the lack of education was basically a precursor to lower income levels, sexual decisions, and access to medical care.

Theme 2: Limited Access to Healthcare.

In Georgia, the lack of public transportation is of main concern for many Black women because they do not have the means to reach certain health facilities for education and assistance. A few of the participants also pointed out that some Black women are not aware of the location of certain health facilities and the programs available. One of the Black women clients believed that lack of transportation also restricted many Black women from getting to healthcare facilities in order to getting testing/medical care. Tanya stated: "Many Black women who are of a lower income level, do not have actual vehicles to get to facilities in order to get tested and they are depending on public transportation that is not running in certain parts of the urban community within Atlanta. I cannot afford a vehicle and I rely on public transportation and in Clayton County, the bus routes were eliminated and I can't get routine access to my OB/GYN visits for myself."

Tanya believes that many Black women who are living in poverty do not have access to transportation due to rural locations were public transportation does not currently run. She discussed that our tax dollars are not going towards the right areas and that funding in public transportation is needed in the metropolitan areas of Atlanta in order to get citizens to the medical care that they need. Elise states: “Resources in the south are extremely limited, and with this area being the ‘bible belt’, many conservative people in charge are making sure that the funding is not there to provide access to the things that many women need to get tested or get healthcare which includes transportation.” Sheree shared:

> The main concern that many of the participants voiced was the fact that ACA is not affordable in Georgia and that the state did not accept certain funding that would provide discounted healthcare plans to the public. I am currently HIV positive and I have experienced the rising costs of healthcare and medicine. The medical copays are killing me and I can’t continue with these payments. I have to choose between eating and paying for my medicine.

Sheree is dealing with a hardship in being able to maintain the medical costs along with her everyday expenses. She discussed that other Black women she knows are dealing with the same issues, particularly those with children because they have to keep themselves healthy in order to care for their families. Sheree believes that the ACA would have been a blessing to someone like her only if Georgia would have accepted funding to reduce the costs of insurance.

Rochelle shared:

> Many Black women cannot afford the health plans, due to leadership in Georgia not accepting federal funding. Elected officials have to take ownership of their decisions and make sure that the ACA is affordable for all. Georgia has limited

> health exchanges compared to other states and that has to change.

Monica stated:

> I believe that the ACA was implemented too fast and it is a great idea but it should have been done in steps. Government officials and the IT structure of the U.S. implemented it too fast and that's why it crashed online initially. People of power who did not understand those who are HIV positive and understanding plans that need to cover medications, labs, and doctor visits put it in place. There were pure navigators to explain the benefits of ACA but there was no real financial literacy component of it and how to afford it. Black women's workload is intense whether it is their health, children, etc. It was a good framework but it was not designed for our community or other communities of color. It's a complex issues, for some ACA was just a Band-Aid.

The main concern for many of the Black women clients was that they would never be able to afford and that they would never be able to get the best level of care that they need to stay healthy. They believe that policymakers in Georgia and nationwide are selfish and do not want to help those who need it the most.

Theme 3: Sexual Health Choices.

Three of the Black women clients interviewed stated that it is hard for Black women in the south to find partners. Carol stated: "I have friends who have told me that they have had a hard time finding someone and when they do, they feel like they have to do whatever they can to keep them and this includes not using protection although they know it is in their best interest."

The consensus from the participants is that Black women are letting their partners take the control in their relationships, which means giving their partners sexual control. Also once Black women are in a relationship, they feel that they no longer need to worry about their sexual health and that includes protecting themselves. The participants discusses that once Black women are in a relationship they feel they are secure enough to proceed without protecting themselves from STDs.

Some of the man sharing is not only between women but also between other men (MSMs). Some of the participants discussed the fact that some men are coming out of jail and are participating in same-sex relationships while behind bars. When they get out, Black women are not suggesting that their partners get tested and are not using protection. In turn, HIV is being transmitted among this group. Elise stated:

> Between February and Mid-April, this time period is when a lot of correctional facilities are releasing inmates from prison and there are not any comprehensive STD resources available in those facilities. The concentration of the virus gets reintroduced within the community. There is a spike around this time of year of testing of Black women because their men are getting out of prison, but then they don't have their partners coming in to get tested. Then the men pass this disease on to their women and have to explain that they were a situational gay while in prison and that is a difficult conversation.

The Black women clients discussed that some Black women are man sharing whether they realize or not and that some just do not care. There is also the issue of mental and physical abuse that some Black women are dealing with in their relationships. Heather shared: “Abusive relationships take away the sexual control from Black women and they have no say in the decisions being made in their relationships. If their partner says they do not want to wear condoms, they go along with it out of fear of abuse.”

One of the participants discussed the fact that programs such as Planned Parenthood have been reduced or eliminated from many lower income neighborhoods. They believe that when these programs are eliminated it takes another resource out of the communities that need it the most and continues to keep many away from the educational opportunities needed to make the right sexual health choices. Monica stated:

> I am not sure of any programs available in my community or even locally in Atlanta. The only thing I know is that I am able to go to my primary care provider. There are no advertisements or other means to really let Black women know about sexual health education courses or assistance. Instead you hear about abortion clinics and ways for Black women to stop reproducing.

One of the participants also discussed that many older Black women who are going back into the dating game due to divorce/death are not protecting themselves against the transmission of HIV/AIDS. Heather shared, “Some older Black women feel untouchable as if they are the ones in control and will not catch HIV/AIDS.” Heather believes that the choices that some of the older Black women are making sexually, is contributing to the spread of HIV/AIDS.

Theme 4: Stigma/Discrimination.

The participants discussed that there is stigma and discrimination surrounding the issue of HIV/AIDS. Some discussed that even going to get tested for the disease brings about stares and underlying feelings about their personal choices as it relates to sex. Many feel as if HIV testing coordinators and administrators do not build rapport with their clients in order to understand their background and the hurdles they are facing. Sheree shared the following:

> I am currently HIV positive and have been diagnosed since 2012. I was sexually promiscuous only because that is what I saw in my community and did not know any better. Having children at a young age and not being in stable relationships is what I learned from my mother and grandmother. Now that I am older I am learning from the mistakes I made while still trying to maintain and afford my health.

Sheree is grateful for the support she has at One Love but she knows that other people, especially Black women are not receiving the care they need because of discrimination. Some of the participants mentioned that they believe that healthcare providers do not care about their wellbeing because of their race. They also feel as if they are discriminated against because they do not have the income to pay for medical expenses as needed. Monica shared:

> I feel that the government plays a large role in what programs are available within urban communities. Without funding, most Black people are not able to get the free services needed to get assistance with their sexual health. Also there are still people and HIV testing coordinators and administrators who are scared to be around those with HIV/AIDS even though they know the details of the disease and how it is transmitted.

HIV Testing Coordinators and Administrators

Theme 5: Provider Empathy and Awareness.

Four of the HIV testing coordinators and administrators discussed concerns regarding provider empathy and concern regarding the health of those who are HIV positive, specifically among Black women. Rachel shared:

> I am currently HIV positive and I remember working at my facility and taking my HIV test out of the blue one day. I left for lunch and came back to see the test showing positive. I took five tests after that including a blood test and they all came back positive. I remember the dread that came over my face but not once did I lose support from my colleagues. This is the same support that they provide for our clients each and every day. It doesn't matter what the issue is, our goal is to make sure that all of our clients gets the support and assistance needed to maintain their health and feel that they have a place that they feel welcomed.

The overall goal of the HIV testing coordinators and administrators at Fulfilled Destiny and One Love is to provide care to anyone and everyone that they encounter. The HIV testing coordinators and administrators have no problem giving care and they want to show those who test positive that there is a light at the end of the tunnel. Terrell stated "I feel that it is my duty to make sure that people of color are treated fairly and with the crisis of HIV/AIDS hitting both Black women and men the hardest, I feel compelled to protect everyone that I come into contact with at this facility." Monet shared, "I got into healthcare to help others in need and be a support system regardless of any disease."

The HIV testing coordinators and administrators want to have positive relationships with their patients and be able to build trust and let them know that people do care. Patricia stated, "I have never seen or known of anyone discriminating against any client based upon their HIV status here at my facility, but I have heard of other facilities who do not build rapport with their clients. Some of them treat their patients like animals in the wild because they do not really care about the people they are servicing." Many of the HIV testing coordinators and administrators felt like their organization did not practice discrimination, but they are aware that there are some within the Atlanta community who do not really empathize with the urban community.

Theme 6: Community Distrust

One of the HIV testing coordinators and administrators mentioned that many Black women have fear of going to the doctor and getting tested. Denise shared:

> Because of past historical incidents, such as the Tuskegee Experiment, many Blacks have ideas that they will be used as guinea pigs for many medical providers. This is something that has been engrained in the minds of many within the Black community. Their fear of not being able to protect themselves from the unknown within the medical establishment can be scary for many.

The participants mentioned that Black women want to have trust with the medical community and that trust is still something that needs to be cultivated into stronger relationships on in this day and time.

Ingrid believes that many Black women feel uncomfortable going to doctors who do not have the same ethnic makeup. She shared, "Black women feel that if they do not have a doctor who looks like them ethnically, they will be judged and will not receive the right type of treatment or will be told erroneous information about their health." These issues have stirred up community distrust among the urban community, which can reduce the likelihood of Black women getting the medical care that they need.

Two of the participants mentioned that the medical community needs to understand the people that they service. Farrah shared, "There need to be more facilities open to provide services for Black women and the healthcare workers within those facilities need to understand their community and the people that they service." Farrah believes that there needs to be sensitivity training for healthcare workers and that there needs to be more involvement in the community. Tyrese stated, "Sometimes, we as healthcare workers, get burnt out and simply have not built the trust we need without clients.” The main consensus from most is that healthcare workers do not always fully understand their community and are not providing the level of empathy needed to help those are connected with HIV/AIDS.

Summary

According to the results, it is evident that many of the behaviors of Black women are correlated to the issues of HIV/AIDS within the south, specifically Georgia. These sexual decisions of Black women are mainly triggered by demographic issues such as lack of income, lower education levels, lack of sexual control, and non-or limited access to medical care. Although the ACA has been solution for many within many urban communities, the costs of the program have limited the choice of many Black women being in charge of their sexual health.

Based upon the interview data, many of the participants believed that Black women who were of a lower SES did not receive the education needed to make the right choices. Also, being in rural areas in the south, transportation is a major issue and cause for concern for those who do not have a means to get to health facilities or testing or adequate medical care. With ACA, the state of Georgia did not accept federal funding and that in turn has increased copays and monthly rates for many. The cost of healthcare is not affordable for many Black women, especially for those on the poverty line.

Some of the participants discussed the issue of sexual control that many Black women are dealing with. The problems of mass incarceration among Black men are of concern due to their HIV status once they are released from jail/prison. Some have taken on MSM relationships while incarcerated and some Black women are not seeking to verify their partners HIV status once they reconnect. There is also the issue of man-sharing (especially in Atlanta where the ratio of women to men is very high) and abusive relationships. Many Black women feel like they cannot ask their partners to protect themselves from fear of being rejected or feel like they will be abused if they say no to certain sexual behaviors.

Based upon the social learning theory, data suggests that cognitive, behavioral, and environmental factors as mentioned in the research are strongly indicative of sexual choices made among Black women. Policy issues such as reduction in funding at many health facilities has taken away the access that many Black women need to get help with their sexual choices whether HIV positive or negative. Living in the south, specifically in Atlanta, GA, some Black women do not feel comfortable dealing with certain health officials and feel that there are stigmas in place and they will be judged due to their status or sexual activity. Many Black women want to be comfortable coming to people within the health community who will not be prejudice against their background or sexual history. Chapter 5 discusses the interpretation of findings along with a summary of the research study.

Chapter 5: Discussion, Conclusion, and Recommendations

Introduction

This chapter includes a discussion of the findings, including integration of Bandura’s social learning theory, a comparison of the findings to broader literature, and policy implications. Based on the interviews and observations conducted, I was able to take a look into the participants’ thought process regarding the phenomenon of HIV/AIDS and its connection to sexual decisions made by Black women in Georgia. Prior to this study, there was limited information or qualitative data from researchers who examined the sexual behaviors of Black women living within the era of HIV/AIDS in the Georgia. In this study, I examined those behaviors by talking to both Black women ages 24-35 and HIV testing coordinators and administrators (which included Black women, or age over 18 years). Due to the rising rates of HIV/AIDS among Black women, it was important to identify the phenomenon and themes that contributed to this issue.

There were three research questions that were used in this study:

- What are the shared experiences of sexual health among Black women in Georgia, specifically from the perspective of both patients and healthcare providers*?*
- How do Black women in Georgia make sense of their sexual health decision making and behaviors within the shifting healthcare climate?

- In what ways do stigma and discrimination inform these women's sexual lives given the climate of HIV/AIDS in the south?

Lack of Education, Limited Access to Healthcare, and *Provider Empathy* answered the research question regarding the shared experiences of sexual health among Black women in Georgia from the perspective of both the Black women clients and HIV testing coordinators and administrators. *Sexual Health Choices* provided information to answer how Black women in Georgia control their sexual health decision making and behaviors within the changing healthcare field. *Stigma/Discrimination* and *Community Distrust* tied up discussion regarding the ways stigma and discrimination may inform these women's sexual lives given the climate of HIV/AIDS in the south.

Black women are dealing with sexual decisions that are greatly affected by environmental factors such as the emulation of observed behaviors. Understanding the reasons behind those behaviors is important. Dodge et al. states:

> Race and ethnicity have served as central organizing concepts in social science and public health research in the United States, although limited attention has been given specifically to the intersections of race/ethnicity and sexual behavior. Over the recent decades, the vast majority of research on the sexual behaviors of Black and Hispanic individuals in the United States has focused on preventive health and sexual risk, often in high-risk samples (including low income, substance abusing, etc.) that are not representative of the general population (2010, p. 330).

The participants discussed the barriers that prevent positive sexual health choices for Black women. The main barriers included Black women growing up in an environment that lacked the support of a school education and limited their potential for income needed to access and afford healthcare. These barriers include the issues of sexual control and stigma/discrimination. Interpreting the findings is important for understanding how to overcome the main barriers that emerged from data collected in this study.

Interpretation of Findings

The social learning theory was used to analyze the findings and investigate how certain behaviors or learned experiences affect the sexual decisions of Black women. Bandura's theory as it relates to the behaviors of Black women, showcases that certain demographic factors are a major part of these behaviors whether cognitive or environmental. The results of the findings showcased environmental factors such as learned and perceived traits, affect the decisions of Black women. The Black women clients discussed that they are a product of their environment and the behaviors that they either encountered or have heard about affected their choices as it relates to sex.

Participants of the study discussed issues such as a lack of education, limited access to healthcare, sexual health choices, stigma/discrimination, and community distrust as reasons for the increased sexual behaviors among Black women in the south, specifically in Georgia. Having discussions with both Black women clients and also HIV testing coordinators and administrators gave insight into the issues that are continuing to affect citizens within Georgia. The phenomenon that was discovered is that shared experiences and learned behaviors attribute to the rising rates of HIV/AIDS among Black women in Georgia and it is not necessarily an individual issue but a systemic community problem. Lack of education, limited Access to Healthcare, and provider empathy answered the central question regarding the experiences of sexual health among Black women in Georgia.

The participants discussed that coming from a lower economic background, many Black women within that community do not receive the education needed to understand the safest sexual choices to make. The participants discussed that younger, lower income Black women are at higher risk of acquiring HIV/AIDS due to limited education. Also, many Black women are not receiving the sexual education needed to remain knowledgeable about HIV/AIDS. Not having a thorough understanding of the disease is partly the reason why many Black women are not receiving the medical care needed, Many Black women have external factors that work against them taking control over their sexual health due to limited access to healthcare and defunding in impoverished communities. These external factors increase the fear that many Black women have with medical facilities.

Five of the participants pointed out that Georgia are greatly affected by the state's rejection of Medicaid expansion by Governor Nathan Deal on April 30, 2014 (Service, 2014). This has caused premiums to be very expensive for individuals and families alike. Black women have dealt with high copays and premiums and cannot afford the costs to continue to make doctor visits along with other health benefits associated with a medical plan. With the rejection of the Medicaid expansion for the healthcare system of Georgia, there is also the issue of the reduction or elimination of sexual health programs for many nonprofit organizations, which include programs geared towards urban communities where the rates of STDs are continuing to rise.

Most of the Black women participants interviewed did not go into detail describing the relationship between the ACA and sexual behaviors. Their main feedback was that the issues they believed affected behaviors were lack of education, lower income levels, and lack of sexual control. There was uncertainty between describing how healthcare and government backing plays a major role in filtering down to communities and keeping programs alive and flourishing. Demographics are a key component in understanding why the sexual behaviors among Black women in Atlanta can be less safe and contribute to the rise of HIV/AIDS. With the ACA increasing their involvement with the healthcare system nationwide and locally, it does not ensure the baseline of quality of care. The participants mentioned that when Black women try to be proactive they are met with shame or stigma, which makes them less likely to return for further care or testing.

The theme of sexual health choices focused on how Black women in Georgia make sense of their sexual health decision making and behaviors within the shifting healthcare climate. Several of the participants discussed that they made many unhealthy sexual choices in the past. They agreed that these decisions could have had a negative effect on their future. Two of the participants who are HIV positive shared their experiences. One of those participants grew up seeing very promiscuous behavior among other Black women in her family and she started having sex early without being educated about STDs and forms of disease transmission. The other participant shared that by working in the healthcare field, she should have been careful in the sexual decisions that she made but assumed that by being in a monogamous relationship she was safe from harm up to and including contracting HIV/AIDS.

The themes stigma/discrimination and community distrust focused on the research question: In what ways do stigma and discrimination inform these women's sexual lives given the climate of HIV/AIDS in the south? As it relates to healthcare, the specific issues that arose from the interviews are that many Black women do not trust healthcare providers. This stems from beliefs that they will be judged or discriminated against if they seek out assistance or education on the topic of their sexual health and avoiding a diagnosis of HIV/AIDS. Cultural insensitivity and ineptness is further complicated by mistrust of public health institutions and the medical profession in general by many Blacks (Melton, 2014). All of the HIV testing coordinators and administrators interviewed verbally stated that there were not any signs of stigma and discrimination in their facilities. Granted, they were in urban communities and were accustomed to building relationships with Black women and other minorities, but they spoke about the trust and care they had for their patients. A majority of the participants discussed the issue that many Black women have is being labeled a *whore*. This is due to them wanting to get tested and knowing their status. Based upon those reasons, the participants believe that Black women fear going to the doctor. The HIV testing coordinators and administrators did discuss the concern that there are some healthcare facilities that do not have the relationships built with their patients and that many Black women and other minorities do not fully trust others who do not necessarily look like them (ethnicity). The participants discussed that Black women and other minorities remember the various experiments and other sterilization techniques used to hinder the progress of minorities in this country. So there is a fear that they will not receive the full care needed for their health or that they will be discriminated against due to their race. It is due to these issues (demographic and policy) overall that the concern of HIV/AIDS has grown into an epidemic among Black women.

Recommendations for Future Research

Further research is needed to explore the phenomenon surrounding the sexual behaviors of Black women and its correlation to HIV/AIDS. The purpose of the research is to understand and discover the reasons behind the increase in HIV/AIDS and how to eliminate or reduce the problems. Dodge et al. stated, "There are gaps that still exist in terms of comprehensive understanding of sexual health among Black and Hispanic individuals outside of the exclusive context of sexual risk and disease transmission" (2010, p. 340). With further qualitative and quantitative research, more data could be collected and analyzed, not only in Georgia but nationwide. A mixed -methods research study is recommended for further research on the topic.

Recommendations: Mixed-Methods Study

A mixed methods approach is a collection of both quantitative and qualitative data sequentially (Creswell, 2009, p. 21). The mixed-methods study should use interview and direct observation techniques, to understand sexual behaviors of various races on the qualitative side. On the quantitative side the study should aim to compare the HIV rates of Black women against others of different races and/or gender.

Direct observation provides a way for the researcher to observe directly what is happening in a contextual setting along with possible participation and interaction involved. Direct observation will provide a way for cross-referencing data collected. It will provide a way to notice any discrepancies between what the participants are saying and what they are actually doing.

Utilizing an interview with a questionnaire attached will allow for an in depth process of understanding the behaviors and allows for a rapport to be built between the researcher and participants. Hopefully, this will open more dialogue and provide for an engaging interview process that will provide more information needed for the study. By conducting research utilizing these qualitative methods, a broader view of the phenomenon can be obtained by the researcher.

On the quantitative side there are numerous sources by organizations such as the CDC, that cite the statistics of HIV/AIDS among Blacks but in understanding data as compared to the qualitative approaches, it is limited. On the quantitative side it should aim to compare the rates of HIV/AIDS cases among Black women to other races, genders, and any other cultural specificities. Doing this will possibly unlock the reason why the rates are increasing so fast as compared to qualitative data based upon the behaviors that have been observed or interviewed.

Looking at both sides of each research approach and combining those together will allow for a greater understanding of the issues of HIV/AIDS among Black women. Realizing the correlation between rates of infection, along with the reasons why those rates are so high, will give a detailed outlook into ways to decrease the spread of the disease. This in turn will hopefully help to reduce stigma and other negative ideas about the disease and open up communication within the community worldwide.

Policy Implications

The purpose of this study is to provide an overview of issues that are affecting the sexual behaviors of Black women and take away the ownership of the guilt that many of them have within the community based upon their own demographic issues and/or policy decisions that are made. The 1990’s saw the emergence of new risk groups during the second bout of the AIDS epidemic and one major group that were affected by the continued threat of HIV were African American women (Gentry et al., 2005). Now in the 2000’s this issue has become a widespread epidemic and is no longer a *potential* threat. The findings of the research indicate a connection between income, education, sexual control, and discrimination/limited access to medical care as attributes to the increasing risk of HIV/AIDS infection. The findings denoted that that Black women who were able to receive education, increase their income, gain control over their relationships, and overcome obstacles regarding fair, complete access to medical care distributed behaviors that reduced the risk of them acquiring HIV/AIDS.

The findings were able to document that Black women sometimes had no control over certain behaviors due to the foundation that was set and behaviors that were either learned, observed, or environmental. What remains unclear is if these unhealthy sexual behaviors can eventually be reversed and if Black women will be able to improve their sexual choices based upon community and governmental activism. The findings of the study was not designed to place the blame of these issues against any one particular group or people, but through analysis of data, common themes were identified that explained many of the issues affecting Black women and related causes.

All of the participants exhibited similar goals in this study, and that was to make sure that a change could be made and the epidemic of HIV/AIDs within the community among Black women could be reduced/eliminated. Data did reveal a slight difference in beliefs in attitudes such as Black women who were educated, married, and had higher levels of income believed that they were almost exempt from the disease because they were monogamous and had a higher level of knowledge on the disease. Those of lower income levels felt that they were not given any type of support to get ahead. The majority of the HIV testing coordinators and administrators felt that they were doing everything they could within their community to help. Although the question was not asked (although one participant willingly provided information regarding their status), one of the HIV testing coordinators and administrators even informed the researcher that two of the HIV testing coordinators and administrators who work at the healthcare facility were HIV positive. This in turn, showed the level of involvement that these health centers had in providing services effectively within the urban community. The research collected will allow others to understand attitudes and behavior and hopefully providing an understanding for all on both sides of the line (medical and community).

Conclusion

The truth about the reasons why HIV/AIDS is such an issue among Black women in today's world is realized through some of the patterns and themes that emerged from the research study which consisted of issues of lack income, lack of education, sexual control, and limited or no access to medical care show. Mona Fouad, director of Minority Health and Disparities Center at the University of Alabama-Birmingham, states, "Many Blacks have no health insurance and a trip to the doctor is a major expense" (Eversley, 2011). Clara Robertson, 52, a volunteer for a program organized by the CDC and the University of Alabama, shares, "In the south it is so different because my mom did not believe in going to the doctor" (Eversley, 2011). Through the findings of the research study, data suggested correlations between low socioeconomic status, limited or no education, lack of sexual control in relationships, provider empathy, and stigma and limited/no access to medical care as precursors to understanding the sexual behaviors that are connected with the increasing spread of HIV/AIDS among Black women. Consistent disparities of HIV/AIDS continue to exist among Black individuals as compared to their White counterparts in the U.S.; Specific factors for higher rates among Blacks are not directly related to race but rather to social and ecological barriers faced by individuals within these communities including racism, poverty; migration, and stigma (Dodge et al., 2010, p. 331).

Harold Henderson, an HIV expert at the University of Mississippi, says southern states suffer from a host of health issues which include HIV, for reasons that include poverty, lack of education, and fragile families (Sternberg and Gillium, 2011). The actions needed to help reduce risky sexual behaviors and the spread of HIV/AIDS in the south will include implementing sexual education programs within the school system, opening and funding community based programs (non-profit or profit), providing sensitivity training for medical providers in understanding the communities that they are working in and assisting, increased public transportation methods, and hopefully the government will provide more affordable ways for the impoverished to access medical care. It is also important to note that since many of the behaviors that lead to the increased risk of HIV/AIDS are learned behaviors, there needs to be more focus on building up the community to help with increasing education, providing more jobs above minimum wage, and providing positive resource outlets for HIV education and assistance. Increasing the knowledge of sexual health with many communities in the south, will help with decreasing the risky sexual behaviors that many Black women are facing and in turn will reduce the negative stereotypes attached this epidemic of a disease

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Appendix A: Black Women Clients

In-Depth Interview Guide A

1. What is your age?
2. What is your current or highest level of education?
3. What is your annual household income?
4. What is your marital status?
5. Describe your background.
6. Describe your ideas about how age, income, and education relate to Black women living with or susceptible to HIV/AIDS
7. Given the current available statistics about HIV/AIDS in Black women, why do you think the South has seen the largest rise of HIV/AIDS cases among Black women?
8. Can you define any differences in sexual decision making made between men and women?
9. If you feel comfortable, please tell us your sexual orientation and thoughts on sexuality?
10. What are your thoughts about the role that sexual orientation may have in relationship to HIV/AIDS among Black women?
11. Have you been tested for HIV, and if you feel comfortable answering this, what were the results?
12. Explain what type of sexual decisions you have made or are making in protecting yourself against HIV.
13. Describe your perception of HIV/AIDS and its effect among minority groups in the south.

14. Explain what type of discrimination, if any, you may have encountered being HIV positive, if HIV negative what type of stigmas do you believe are associated with HIV.

15. Describe your thoughts regarding the Affordable Care Act (nation's health reform law enacted in 2010) and relationship to HIV/AIDS among Black women.

16. Describe your thoughts on access to healthcare in the south, specifically Georgia, for Black women.

17. What type of education programs regarding sex have you been to, heard of, or seen within your community or this health facility?

18. What can the government or healthcare facilities do to assist Black women with decreasing the spread of HIV/AIDS?

19. Explain how your ideas regarding healthcare facilities and/or workers that may discriminate against those with HIV/AIDS.

Appendix B: HIV testing coordinators and administrators

Interview Guide B

1. What is your age?
2. What is your race?
3. What is your current job and title?
4. How long have you been working in healthcare?
5. Explain your role in dealing with HIV testing?
6. Describe your thoughts on the Affordable Care Act (nation's health reform law enacted in 2010) and its relationship to Black women living with HIV/AIDS.
7. Who do you believe minorities has the highest incidence of testing HIV positive and why?
8. What are your thoughts about giving care to those who are HIV positive?
9. What type of behaviors do you believe that individuals are engaging in who are HIV positive?
10. Do you think there is a stigma and discriminatory practices within your facility related to HIV/AIDS and if so why?
11. Do you think there is an issue of stigma and discrimination overall with HIV/AIDS?
12. Explain the types of health concerns that you hear from Black women living with HIV/AIDS who come to your facility?
13. Explain the type of assistance and programs you have available for educating others on HIV and for those who are HIV positive?
14. Describe what demographic variables may be affecting the rise of HIV/AIDS among Black women in the south.
15. What type of community and social concerns do you hear regarding HIV/AIDS in your city?

16. Why do you think that Black women are seeing the highest transmission of HIV/AIDS, specifically in the south?

17. What type of disparities have you seen in screening Black women for HIV/AIDS?

18. Are there any programs related to HIV/AIDS that have been reduced/eliminated within your facility or area?

19. Do you feel that there is distrust from the Black community regarding the medical establishment for patients who have HIV/AIDS? If so why?

20. Describe your ideas about being able to care for your patients living with HIV/AIDS.

21. Do you think there is a variation in patients ability to access care and if so why?

22. Do you think that any particular patients have more difficulty accessing care?

23. Given the current available statistics about HIV/AIDS in Black women, why do you think that the south has seen the largest rise of HIV/AIDS cases among Black women?

Appendix C: Secondary Data

Interview Guide A

Question 1: What is your age?

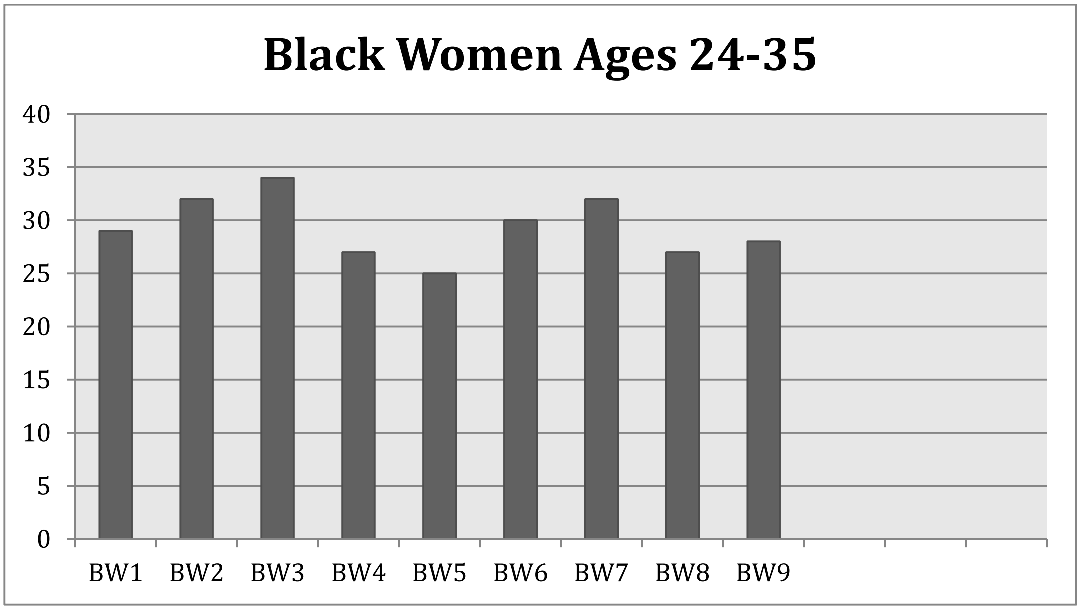

Figure 4: Age of Black Women (BW) Participants

Question 2: What is your current or highest level of education?

ALICE: GED

BEATRICE: High School Diploma

CAROL: JD

ELISE: Masters

HEATHER: EdD

MONICA: PhD

ROCHELLE: 10th Grade

SHEREE: 12th Grade

TANYA: Masters

Question 3: What is your annual household income?

ALICE: $25,000/year

BEATRICE: $35,000/year

CAROL: $150,000/year

ELISE: $12,,000/year

HEATHER: $35,000/year

MONICA: $75,000/year

ROCHELLE: $5,000/year

SHEREE: $10,000/year

TANYA: $40,000/year

Question 4: What is your marital status?

ALICE: Married

BEATRICE: Single

CAROL: Divorced

ELISE: Divorced

HEATHER: Single

MONICA: Single

ROCHELLE: Single

SHEREE: Married

TANYA: Single

Question 5: Describe your background?

ALICE: I come from a family of two siblings and we were raised in the south. I married young at 19 and currently have two children.

BEATRICE: I am single, never married and no children. I do not see myself every getting married or having children.

CAROL: I divorced a few years ago. I have one child and I was born and raised in New York City and have lived in Georgia for the past 10 years.

ELISE: I am currently divorced (but engaged to be married again) and no children. I was married for two years and divorced. I was born and raised in Atlanta, GA.

HEATHER: I am currently single with no children. I have lived in the south for my whole life.

MONICA: I am single. I went to a historically Black college (HBCU) in the south.

ROCHELLE: I have never been married and I have four children. I have lived in Atlanta for the past 15 years.

SHEREE: I am married.

TANYA: I am from California. I do not have any children but I do have stepchildren from my former marriage.

Question 6: Describe your ideas about how age, income, and education relate to Black women living with or susceptible to HIV/AIDS.

ALICE: Older women getting into the dating world are at increased risk. The more education the less risky behaviors so I think the rate of infection is lower and with more money women tend to be more cautious.

BEATRICE: I think income and education has a direct effect on availability of resources.

CAROL: I believe that life happens. No one deserves to be sick and those who have HIV should be treated the same as anyone who is ill.---with kindness, care and proper medical treatment.

ELISE: Lack of money to obtain condoms. The elderly do think about AIDS because it wasn’t around for most of their lives.

HEATHER: It seems that younger lower income women tend to subject themselves to a lower level of living, which perhaps could be a characteristic of that level. I have also heard that older women that are single or widowed have fallen into the trap of subjecting themselves to any type of sex due to being lonely. This may lead to unprotected sex, etc.

MONICA: I think it is important for young African American women to be knowledgeable about HIV and ways in which it can be contracted. Unfortunately, I believe that African American women from lower socioeconomic status aren’t as knowledgeable as they need to be about HIV.

ROCHELLE: I think that women of any age make careless choices. In some cases it’s because of age, but others, I’m sorry to say, is just not being careful.

SHEREE: There is no guarantee, You can control your sexual partner regardless of your age, income, or education.

TANYA: It depends on the exposure and education about health.

Question 7: given the current available statistics about HIV/AIDS in Black women, why do you think the south has seen the largest rise of HIV/AIDS cases among Black women?

ALICE: There may be more women trying to get a man with such limited numbers of men.

BEATRICE: Poverty, higher women to men ratios that lead to risky sexual behaviors out of desperation.

CAROL: I believe that as a community we have a hierarchy of illnesses and unfortunately sexually transmitted diseases is at the bottom. Consequently, people are afraid to disclose their status and seek treatment.

ELISE: It is a struggle for Black women to find mates down here so women are loose to catch a man. They don't want to have the discussion about protection for fear of turning off the guy.

HEATHER: Perhaps the ability to seem naïve. The northern women are more likely to stand up for what they believe, not caring about the outcome.

MONICA: Lack of educational opportunities

ROCHELLE: High levels of Black women competing for Black men mean that women are wiling to accept poor behavior from men.

SHEREE: The reporting centers are public health centers. Private offices may not report as readily. Concentration of affected areas should be considered for ratio.

TANYA: Lack of access to education and healthcare.

Question 8: Can you define any difference in sexual decision making made between men and women?

ALICE: Women tend to be led by their partner’s decision and men take charge.

BEATRICE: Some women tend to stay on top of their medical decisions in sexual health as compared to men.

CAROL: Women feel the need to do whatever their man wants.

ELISE: Some women want to make sure that they are taking the appropriate health precautions in sex as compared to men.

HEATHER: Women feel that when they are in a relationship they no longer need to protect themselves. The same goes with the men.

MONICA: Women do not have the sexual control in many relationships and feel the need to prove a point to their men.

ROCHELLE: Some women are not educated on ensuring their sexual health.

SHEREE: Women like to take control in their sexual decisions and sometimes will not proceed further without ensuring their sexual health is in tact

TANYA: Sometimes both genders like to pretend about things without really knowing the sexual implications that will follow.

Question 9: If you feel comfortable, please tell us your sexual orientation and thoughts on sexuality.

ALICE: I am heterosexual. I do not believe in alternate lifestyles.

BEATRICE: I am a lesbian and I think you fall in love with whomever you want. You can't stop it.

CAROL: I am heterosexual. I believe that everyone has a choice to make their own decisions on whom they want to be with sexually.

ELISE: I am heterosexual. I believe to each its own.

HEATHER: I am heterosexual. I believe in pro-choice for whomever you love.

MONICA: I am heterosexual. I don't have any feelings or thoughts towards it.

ROCHELLE: I am bi-sexual. I lean more towards men but I enjoy women also.

SHEREE: I am heterosexual. The world has changed and you can't tell a person whom to love.

TANYA: I am heterosexual. I have a few LGBT people in my family and it has been a hard adjustment with their sexuality due to how I was raised coming from a Christian family.

Question 10: What are you thoughts about the role that sexual orientation may have in relationship to HIV/AIDS among Black Women?

ALICE: I am not sure, but I don't think sexual orientation will cause an increase.

BEATRICE: I think men on the down low who engage in risky sexual behaviors contribute to higher HIV/AIDS rates among Black women.

CAROL: I am not sure on the role of sexual orientation but I know that as a community we ostracize people who don't identify as heterosexual. That is something that we will need to change.

ELISE: Down low homosexual men are being reckless and coming home to their wives or partners.

HEATHER: Many more Black women may have AIDS and not realize it..perhaps the not knowing is more soothing than knowing???

MONICA: No answer

ROCHELLE: I think that more straight women have HIV/AIDS than gay women.

SHEREE: No answer

TANYA: No Answer

Question 11: Have you been tested for HIV, and if you feel comfortable answering this, what were the results?

ALICE: Negative, I am married

BEATRICE: Yes, negative. Getting tested annually. Not engaging in unprotected sex.

CAROL: I tested negative for HIV. I have had limited sexual partners and I became sexually active much later than my peers. I have vivid memories of the initial AIDS crisis, and the paranoia that accompanied it. I admit that I started sexual relationships using condoms and as trust developed, we stopped. I know that wasn’t smart as one can’t visually discern sexually transmitted disease, but that’s what we did.

ELISE: I get tested every year. I make sure my husband gets tested every year and I see the results.

HEATHER: Condoms or no sex at all.

MONICA: No, married

ROCHELLE: I am HIV positive and I acquired it through heterosexual sex.

SHEREE: Yes. Negative. Protected sex, abstinence, and/or single partner.

TANYA: Yes and negative.

Question 12: Explain what type of sexual decisions you have made or are making in protecting yourself against HIV.

ALICE: I am married, so I do not use protection. Before, I was married I used protection unless I knew for sure I was in a monogamous relationship.

BEATRICE: I use protection but I will admit that I have captured an STD in a past relationship. I try to stay on top of my sexual health.

CAROL: I am in a long-term relationship and I do not use protection.

ELISE: I do not use protection as I am currently married.

HEATHER: I am currently celibate.

MONICA: I am married and we do not use protection. Before we married, we used protection.

ROCHELLE: I am single and date but I only have had two sexual partners in the past two years and we used protection and I refuse to have sex without it.

SHEREE: I am married and we do not use protection. I will admit that I was careless with protection while we were dating. I am glad that I never caught an STD.

TANYA: I do not use protection as often as I need to. When I feel that I am in a monogamous relationship, protection normally goes out of the window.

Question 13: Describe your perception of HIV/AIDS and its effect among minority groups in the south.

ALICE: Black people in general do not protect themselves once in a relationship. Then you have some who are cheating and catching diseases and bringing it back to their partner.

BEATRICE: In the south, there is nothing to do but have sex and get pregnant. That is why rates are so high specifically among Black women.

CAROL: HIV/AIDS is an epidemic that has been built up by the Government to knockout minorities and reduce our population.

ELISE: Black women are dealing with MSMs and catching diseases left and right from their partners who are suppose to be heterosexual.

HEATHER: In the south, we do not have the transportation or medical care needed to provide support for minorities.

MONICA: Initially, HIV/AIDS was a gay white men epidemic, I am not sure how it turned into a “Black” issue with so many cases spreading, specifically across rural areas in the south.

ROCHELLE: I think it is somewhat of a conspiracy and that the rate of infections among minorities, specifically Blacks, is exaggerated.

SHEREE: Minorities do not get a fair chance in the south with having the access to education to take control of their sexual health.

TANYA: Most Black women are dealing with low self-esteem and other issues when it comes to their partners. They are seeing their Black men locked up then come out and the disease is continuously spreading through the community.

Question 14: Explain what type of discrimination, if any, you may have encountered being HIV positive, if HIV negative what type of stigmas do you believe are associated with HIV?

ALICE: There are many stigmas such as fear of transmission through just a touch.

BEATRICE: Many of the stigmas are people having the fear of the unknown and not really understanding the disease.

CAROL: Many people still do not understand that HIV/AIDS is not the same that it was years ago. There are lots of treatments and medicines to keep the disease in check.

ELISE: People like to discriminate and do not realize that you might have encountered anyone HIV positive and did not even know it. It is not a disease that is written on someone’s chest.

HEATHER: I am not HIV positive but I have a family who is and the lack of medical care they are receiving and the costs have had a detrimental effect on their health.

MONICA: Many people believe it is a dirty person's disease.

ROCHELLE: With me being HIV positive, I have encountered costly prescriptions, not getting adequate care from medical providers, and feeling like I am being judged from others who have no idea what type of person I am.

SHEREE: I am not totally comfortable being around people whom I know are HIV positive but I do believe that everyone should be treated fairly.

TANYA: People can live with the disease now and still remain healthy. Others should realize that and get over it.

Question 15: Describe your thoughts regarding the Affordable Care Act (nation's health reform law enacted in 2010) and relationship to HIV/AIDS among Black women.

ALICE: I think the rate of infection should decrease because more people will be able to access healthcare.

BEATRICE: ACA makes it possible to have more access to healthcare where it is available.

CAROL: I'm not sure how the AC is applied to HIV/AIDS positive people but I hope that their medicines and treatment options are included and treated the same as other illnesses.

ELISE : I don't have any thoughts on this.

HEATHER: This should give more opportunities to be tested.

MONICA: Having affordable health insurance is a positive step to support women's knowledge about HIV.

ROCHELLE: I'm not sure how the ACA relates to HIV/AIDS among Black women.

SHEREE: No thoughts. Hope there's a way to have more preventive education.

TANYA: Has not educated public about how health benefits can cover costs of testing.

Question 16: Describe your thoughts on access to healthcare in the south, specifically Georgia for Black women.

ALICE: I think access is good in urban areas but the care for rural areas is not as readily available.

BEATRICE: I think resources in the south, especially the rural south are extremely limited, which makes it difficult. Also, the "bible belt" prevents straightforward sex education from occurring.

CAROL: I believe that the southern states decision not to participate in the broader exchanges have affected southerners. Our costs are more for health insurance and our network is limited.

ELISE: Healthcare in metro areas is ok. In rural Georgia, however, there is a significant need for better access and resources. AIDS is a silent killer that is spreading to Black women through down low men.

HEATHER: Healthcare all around can be risky. Insurances have hidden fees that make people shy away from the proper care. This could be one of the leading causes that the proper care is not sought after. Also, the myth in the Black community that doctors make you more ill could also be a factor.

MONICA: No answer.

ROCHELLE: There are either highly educated women or very under educated women.

SHEREE: No answer.

TANYA: Women seem to fear the diagnosis.

Question 17: What type of education programs regarding sex have you been to, heard of or seen within your community or this health facility?

ALICE: I hear about Planned Parenthood but not many more.

BEATRICE: I am not sure of any programs in my neighborhood.

CAROL: I have not heard of any.

ELISE: I just only hear about Planned Parenthood nationwide.

HEATHER: I don’t know of any programs.

MONICA: I am not sure of any programs.

ROCHELLE: I know of local programs in my area but before I became HIV positive, I only knew of going to my regular doctor or OB/GYN for assistant with HIV or STD testing.

SHEREE: I don’t know of any specific programs geared towards HIV testing.

TANYA: I am not sure of any programs.

Question18: What can the government or healthcare facilities do to assist Black women with decreasing the spread of HIV/AIDS?

ALICE: Provide programs that are free for the public for HIV/Sex awareness.

BEATRICE: Stop taking away the funding nationwide and locally. Our governor of Georgia has reduced a lot of the educational programs in the schools.

CAROL: Learn about the communities that you accept as patients. Understand their plight and what they are going through.

ELISE: Provide the programs needed to assist Black women and other minorities with their sexual health.

HEATHER: The government and health facilities need to bring back programs and advertise those programs, specifically in communities that are impoverished.

MONICA: Stop defunding urban communities.

ROCHELLE: Provide us with assistance with being able to pay for medical costs in order to afford the medication needed to sustain being HIV positive.

SHEREE: We need more funding in lower income communities.

TANYA: More funding for the programs needed to make others aware of Sexual health.

Question 19: Explain your ideas regarding healthcare facilities and/or workers that may discriminate against those with HIV/AIDS.

ALICE: Many facilities do not want to deal with people who do not have medical care period. The first thing they ask is “Can I see your medical?” without any compassion for what they may be dealing with.

BEATRICE: Some medical people are burnt out and do not have the empathy to deal with patients. They need to take sensitivity training.

CAROL: Some workers do not want to deal with anyone who has diseases out of fear

ELISE: They can sometimes stereotype others and look down on minorities, which is why it is hard to get those who need to be tested to the doctor.

HEATHER: Healthcare facilities and workers need to understand the community that they are in or the people they service.

MONICA: Most healthcare places need to understand what the community needs and help as much as they can.

ROCHELLE: These places need to go out of business if they are not truly going to help others specifically those who really need it.

SHEREE: Understand the things needed to make sure your patients feel safe. Get involved in community events.

TANYA: Please start free programs to provide education resources in urban communities.

Interview Guide B

Question 1: What is your age?

CHRIS: 28

DENISE: 48

FARRAH: 44

INGRID: 30

LISA: 30

MONET: 56

PATRICIA: 52

RACHEL: 35

ROLAND: 31

STEVE: 24

TERRELL: 28

TYRESE: 26

Question 2: What is your race?

CHRIS: African American

DENISE: African American

FARRAH: White

INGRID: Black

LISA: Filipino/Moroccan/Spanish

MONET: Black

PATRICIA: African American

RACHEL: Black

ROLAND: African American

STEVE: African American

TERRELL: Black

TYRESE: African American

Question 3: What is your current job title?

CHRIS: HIV Prevention Specialist

DENISE: Prevention Specialist/Testing Counselor

FARRAH: Prevention Intern/Health Education

INGRID: HIV Prevention Specialist

LISA: Law and Policy

MONET: Prevention Specialist

PATRICIA: Associate Bridge Leadership Program Rep

RACHEL: Program Manager

ROLAND: Program Manager

STEVE: Intern

TERRELL: AmeriCorps Member

TYRESE: Support Services Coordinator

Question 4: How long have you been working in healthcare?

CHRIS: 1 year

DENISE: 7 years

FARRAH: 25 years

INGRID: 10 years

LISA: 5 months

MONET: 20 years

PATRICIA: 12 years

RACHEL: 14 years

ROLAND: 7 years

STEVE: 3 months

TERRELL: 1 year

TYRESE: 1 year

Question 5: Explain your role in dealing with HIV testing?

CHRIS: Do the testing and give results.

DENISE: Work on research projects, prevention, and educating the community how HIV plays a role in community

FARRAH: Oversee clients, conduct testing, counseling, and risk reduction plans.

INGRID: Perform testing services.

LISA: Analyze testing and counseling procedures.

MONET: Oversee HIV testing, risk reduction plans, and counseling.

PATRICIA: Oversee testing and counseling (pre and post).

RACHEL: Oversee clients doing consent forms, take clients to testing room, do urine samples, counseling, and risk reduction plan.

ROLAND: normalize experience creating sense of urgency/mobilizing to act as navigators.

STEVE: Counsel people to help normalize the disease; prompt people to engage.

TERRELL: Guide them through the process of paperwork; showing how to get from point A to point B.

TYRESE: No answer

Question 6: Describe your thoughts on the Affordable Care Act (nation's health reform law enacted in 2010) and its relationship to Black women living with HIV/AIDS.

CHRIS: Nothing; it's not helping anyone positively; Paying for medications is not helping

DENISE: Georgia does not make it feasible for Black women to use healthcare (there are hurdles for Black women with getting healthcare).

FARRAH: It's a step in the right direction/many people do not how where to get counsel/rates are high; Some do not have access to computer systems.

INGRID: Don't know; It's better health insurance?

LISA: ACA has allowed more people to be covered and the Medicaid expansion has left a gap. The gap includes a percentage of Blacks). Black women are the 2nd most affected in Georgia.

MONET: I have a sister who has ACA and in January she will not be covered. It would be better if it were easier and affordable. It seems hard to get coverage.

PATRICIA: I thought it was good in the beginning. Many struggle with seeing the benefits due to co pay. What about those with no income who can't receive it? Many have to decide whether to get coverage or feed their children.

RACHEL: For those who don’t have healthcare it has made it more affordable, especially with having scheduled exams.

ROLAND: It is an amazing framework; Healthcare has some drawbacks put in place by people of privilege. Women who may be HIV positive only get certain things covered.

STEVE: It is helpful but too expensive. The penalty is not great for those with a low income.

TERRELL: It was implemented too fast. It is great to have but should have been done in steps; The IT structure was implemented too fast; In many areas it is missing target areas and the people who are struggling are being missed.

TYRESE: No answer

Question 7: Why do you believe minorities has the highest incidence of testing HIV positive and why?

CHRIS: Want to have sex (testing the waters).

DENISE: Economics, accessibility to healthcare, knowledge, and comfortability.

FARRAH: Fear factor, Socioeconomic, lack of education on getting HIV, and getting the word out.

INGRID: Minorities do not come and get tested and treated and they do not have health insurance

LISA: Social and sexual networks (concentrated pool of people who are having sex with each other), LGBT come to Atlanta and increase the rates. Lack of sex education talks.

MONET: They don't want to know and believe that it can't happen to them. Also, not being able to pay for services.

PATRICIA: Because the community is sharing partners and there are not many men available.

RACHEL: It is not a priority for them and there are so many other pressing things that require attention.

ROLAND: Many are met with shame or stigma, lack of education, stress of being a minority. Stress leads to lack of prioritizing and shame. Some have unchecked viral loads (between 3-6 months) and correction facilities releasing inmates.

STEVE: Fear of knowing. Black people do not like to go to the doctor until they are really sick.

TERRELL: Lack of education, mentality of apathy, Men minorities have different ways of doing things.

TYRESE: Bringing in men once they get out of jail and wanting to get tested to then find out they were HIV.

Question 8: What are your thoughts about giving care to those who are HIV positive?

CHRIS: No issues. It is challenging letting them know they are HIV positive.

DENISE: It's necessary.

FARRAH: We need to lessen the stigma. No different then treating a normal person who is HIV negative. There is not much of a fear from a provider standpoint.

INGRID: I want to provide them with the best care and it's hard to tell them that they are HIV positive.

LISA: If you don't take a stance on human rights issues then you are a part of the problem. Community work is gratifying.

MONET: I do not treat them different.

PATRICIA: I like helping people and enjoy watching people grow and getting people in a better place.

RACHEL: I make sure they get treatment adherence and I don't treat them differently and hand walk them through the steps.

ROLAND: I don’t believe in care, I believe in improving quality of life.

STEVE: no answer

TERRELL: It’s a mirror ball, Support is paramount and holistic health is great and long-term support is needed.

TYRESE: Tailored and comprehensive to that client and understand when the client is in need.

Question 9: What type of behaviors do you believe that individuals are engaging in who are HIV positive?

CHRIS: Sexual acts continuing on.

DENISE: Sharing partners (whether they know it or not) and unprotected sex.

FARRAH: Unprotected sex, multiple partners, Male sex with Men.

INGRID: Unprotected sex and intravenous drug use.

LISA: Not using condoms and IV drug use.

MONET: Not knowing their status.

PATRICIA: Falling in love and having sex. 85% are disclosing their HIV status.

RACHEL: Unprotected sex.

ROLAND: The intention and motivation is different and those who are HIV positive may deny.

STEVE: no answer

TERRELL: The same activities that have been going on since the beginning of time.

TYRESE: Same behaviors as those who are HIV positive or negative and practicing some of the same behaviors.

Question 10: Do you think there is a stigma and discriminatory practices within your facility related to HIV/AIDS and if so why?

CHRIS: No

DENISE: No

FARRAH: No

INGRID: No

LISA: No

MONET: No

PATRICIA: No

RACHEL: No

ROLAND: No

STEVE: No

TERRELL: No

TYRESE: No

Question 11: Do you think there is an issue of stigma and discrimination overall with HIV/AIDS?

CHRIS: Yes

DENISE: Yes

FARRAH: Yes

INGRID: Yes, people still think of it as a nasty disease and people do not understand it. Schools are not educated about it anymore.

LISA: Yes, stereotypes from years ago that it was a gay disease and not having a culture that promotes diverse culture. Racism, infrastructure, poor socioeconomic status will not give you access to healthcare.

MONET: Yes

PATRICIA: Yes

RACHEL: Yes

ROLAND: Yes

STEVE: Yes

TERRELL: Yes

TYRESE: Yes

Question 12: Explain the types of health concerns that you hear from Black women living with HIV/AIDS who come to your facility?

CHRIS: Not having transportation for healthcare and mental health doctors.

DENISE: Cost of meds, side effects of medication, and accessibility to healthcare.

FARRAH: no answer

INGRID: Heart issues and issues with tainted water within their community.

LISA: Side effects form medication, heart conditions, high rates of other STDS, and reproductive health issues.

MONET: Compromised issues with immune system. Dual diagnoses such as Hepatitis C and HIV.

PATRICIA: Younger ages may be convinced to have an abortion and being able to have children. Having providers or doctors who are going to treat them fairly if HIV positive.

RACHEL: Homelessness, drug use, and prostitution.

ROLAND: Women are asking how do they live with HIV.

STEVE: no answer

TERRELL: Mental health concerns.

TYRESE: Mental health and providing a level of care and emotional help.

Question 13: Explain the type of assistance and programs you have available for educating others on HIV and for those who are HIV positive?

CHRIS: Everyone has a story. We offer support groups.

DENISE: Support programs. We offer literature, brochures, and trainings.

FARRAH: We go to churches, malls and handing out info. We have a linkage program (STD and treatment program)

INGRID: We conduct focus groups.

LISA: We have early intervention programs and culturally relevant parties talking about various subjects.

MONET: We go to the methadone clinic to do outreach.

PATRICIA: We offer secondary prevention programs, which stops a person from being re-infected with HIV.

RACHEL: We offer outreach programs.

ROLAND: Mobilization (community outreach), testing, volunteer.

STEVE: no answer

TERRELL: no answer

TYRESE: Abortion clinic program, planned parenthood and job readiness skills.

Question 14: Describe what demographic variables may be affecting the rise of HIV/AIDS among Black women in the south.

CHRIS: People are not educated on HIV.

DENISE: Economics, education, transportation.

FARRAH: Lack of education and accessibility to health facilities.

INGRID: Rural areas (there is nothing to do) and everyone is sleeping with everybody.

LISA: Income, violent relationships (not having power to have sexual control), level of education, area code and its correlation to poverty in a micro location (poor area)

MONET: Transportation to get care.

PATRICIA: Economic, health disparities, and fear

RACHEL: Socioeconomic status, education (most have no High School diploma).

ROLAND: HIV has stigma in the south and we are in a conservative Christian culture.
HIV is considered deviant behavior.

STEVE: No answer

TERRELL: At a certain age we feel invincible.

TYRESE: No answer

Question 15: What type of community and social concerns do you hear regarding HIV/AIDS in your city?

CHRIS: People not knowing were the testing facilities are located.

DENISE: With HIV being 30 plus years, we are still having the same practices (behaviors not changing).

FARRAH: Black women do not trust boyfriends but do not get them to use condoms.

INGRID: I haven’t heard much.

LISA: It is difficult to keep people in stable and affordable housing. Large portions of homeless people are young LGBT. If they don’t have anywhere stable to stay, they can’t maintain their health.

MONET: no answer

PATRICIA: People are still uneducated and still think it can’t be transmitted freely/misinformation.

RACHEL: Some organizations can only test in priority zip codes (considered high risk).

ROLAND: no answer

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 16: Why do you think that Black women are seeing the highest transmission of HIV/AIDS, specifically in the south?

CHRIS: Down low men (some men are using apps to connect with gay men).

DENISE: Our policy makers that have control over certain policies make it difficult for us to get the education, healthcare,. In the south you are too comfortable.

FARRAH: Many are afraid to ask for partner to wear condom and deal with physical abuse.

INGRID: Unprotected sex; rise of MSMs.

LISA: Income and level of education.

MONET: Unprotected sex

PATRICIA: Fear of not wanting to know, stigma, man sharing, and lack of education.

RACHEL: Unprotected sex.

ROLAND: Man sharing, sex has become transactional and the social norm.

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 17: What type of disparities have you seen in screening Black women for HIV/AIDS?

CHRIS: I haven't seen any

DENISE: Black women are not knowledgeable.

FARRAH: Money

INGRID: Black women do not want to get tested unless they are handing out something free.

LISA: Some doctors screen people in Atlanta and discriminate and some feel that they are not treated with respect.

MONET: Money

PATRICIA: Concerned about financial cost

RACHEL: Money

ROLAND: Single homes, multiple children, and underlying stigma.

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 18: Are there any programs related to HIV/AIDS that have been reduced/eliminated within your facility or area?

CHRIS: No

DENISE: Funding

FARRAH: No

INGRID: No

LISA: No

MONET: Some programs like eliminating the breeze card (public transportation card).

PATRICIA: No

RACHEL: No

ROLAND: Food pantry/clothing

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 19: Do you feel that there is distrust from the Black community regarding the medical establishment for patients who have HIV/AIDS? If so why?

CHRIS: No

DENISE: Yes, they think it's the government/it's not real to them. Black people still remember the Tuskegee experiment.

FARRAH: Yes, doctors are not effective communicators.

INGRID: Yes, some facilities need to be updated and they are cramped.

LISA: Yes, some feel they have a possibility of having a better quality care when dealing with their own ethnic group.

MONET: Sometimes they don't trust that doctors are doing what they are supposed to do.

PATRICIA: Tuskegee experiment (past history with medical facilities) gives a sense of hesitation.

RACHEL: Yes, due to cultural competence.

ROLAND: Yes, due to customer service and fear of seeing someone they know.

STEVE: No answer

TERRELL: No answer

TYRESE: No answer

Question 20: Describe your ideas about being able to care for your patients living with HIV/AIDS.

CHRIS: NO

DENISE: Treat them as individuals, respect, and decency and treat everyone the same. I want to help them receive the care without stigma.

FARRAH: I want to help build relationships with the women.

INGRID: I lead them to the resources needed to help to get them what they need.

LISA: Build relationships, trust and treat them with respect.

MONET: I will make sure that I am keeping confidentiality.

PATRICIA: Encouraging them to get mental health services (Most Black people do not get mental health).

RACHEL: Providing support groups and calling them up.

ROLAND: no answer

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 21: Do you think there is a variation in patient's ability to access care and if so why?

CHRIS: No

DENISE: Income (better income/more accessibility).

FARRAH: Yes, due to transportation.

INGRID: Some patients do not know how to get to care.

LISA: Yes, because of being uninsured, not having education.

MONET: Yes

PATRICIA: Educational skills (were not all on the same level).

RACHEL: Yes, having access to medical care.

ROLAND: no answer

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 22: Do you think that any particular patients have more difficulty accessing care?

CHRIS: No

DENISE: Disabled patients (it is not easy for them).

FARRAH: They all have the same issues.

INGRID: Those with no transportation.

LISA: Black men 18-54 are least likely to seek medical care (highest rates of new HIV cases).

MONET: They all have the same issues.

PATRICIA: Younger people (Having to take care of themselves/they are invincible and having to go to a doctor is hard) and older people (distraught and ashamed about having the disease).

RACHEL: They all have the same issues.

ROLAND: no answer

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Question 23: given the current available statistics about HIV/AIDS in Black women, why do you think that the south has seen the largest rise of HIV/AIDS cases among Black women?

CHRIS: People not caring and not being educated.

DENISE: Lack of education, accessibility, and comfortable in our behaviors (due to economic status).

FARRAH: People are transient (there are more opportunities to have sex).

INGRID: More MSM’s, sex education is not talked about consistently in the south due to this area being the bible belt.

LISA: Lack of insurance, lack of sex education, and people not caring. Elected officials, staff, and leadership not caring about housing, employment and transportation.

MONET: People are transient.

PATRICIA: Men are locked up (sharing the same men), health disparities/not having the finances and/or self esteem.

RACHEL: South is transient/there are a lot of people who have moved down here from the north.

ROLAND: There is an HIV treatment cascade of getting tested vs. virally suppressed.

STEVE: no answer

TERRELL: no answer

TYRESE: no answer

Appendix D: HIPAA

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[*45 CFR 164.501, 164.508,*
164.512(i)]
[See also *45 CFR 164.514(e), 164.528,*
164.532]

Background

The HIPAA Privacy Rule establishes the conditions under which protected health information may be used or disclosed by covered entities for research purposes. Research is defined in the Privacy Rule as, "a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge." See 45 CFR 164.501. A covered entity may always use or disclose for research purposes health information which has been de-identified (in accordance with 45 CFR 164.502(d), and 164.514(a)-(c) of the Rule) without regard to the provisions below.

The Privacy Rule also defines the means by which individuals will be informed of uses and disclosures of their medical information for research purposes, and their rights to access information about them held by covered entities. Where research is concerned, the Privacy Rule protects the privacy of individually identifiable health information, while at the same time ensuring that researchers continue to have access to medical information necessary to conduct vital research. Currently, most research involving human subjects operates under the Common Rule (45 CFR Part 46, Subpart A) and/or the Food and Drug Administration's (FDA) human subject protection regulations (21 CFR Parts 50 and 56), which have some provisions that are similar to, but separate from, the Privacy Rule's provisions for research. These human subject protection regulations, which apply to most Federally-funded and to some privately funded research, include protections to help ensure the privacy of subjects and the confidentiality of information. The Privacy Rule builds upon these existing Federal protections. More importantly, the Privacy Rule creates equal standards of privacy protection for research governed by the existing Federal human subject regulations and research that is not.

How the Rule Works

In the course of conducting research, researchers may obtain, create, use, and/or disclose individually identifiable health information. Under the Privacy Rule, covered entities are permitted to use and disclose protected health information for research with individual authorization, or without individual authorization under limited circumstances set forth in the Privacy Rule.

Research Use/Disclosure Without Authorization. To use or disclose protected health information without authorization by the research participant, a covered entity must obtain one of the following:

- Documented Institutional Review Board (IRB) or Privacy Board Approval. Documentation that an alteration or waiver of research participants' authorization for use/disclosure of information about them for research purposes has been approved by an IRB or a Privacy Board. See 45 CFR 164.512(i)(1)(i). This provision of the Privacy Rule might be used, for example, to conduct records research, when researchers are unable to use de-identified information, and the research could not practicably be conducted if research participants' authorization were required.

  A covered entity may use or disclose protected health information for research purposes pursuant to a waiver of authorization by an IRB or Privacy Board, provided it has obtained documentation of *all* of the following:

  - Identification of the IRB or Privacy Board and the date on which the alteration or waiver of authorization was approved;
  - A statement that the IRB or Privacy Board has determined that the alteration or waiver of authorization, in whole or in part, satisfies the three criteria in the Rule;
  - A brief description of the protected health information for which use or access has been determined to be necessary by the IRB or Privacy Board;
  - A statement that the alteration or waiver of authorization has been reviewed and approved under either normal or expedited review procedures; and
  - The signature of the chair or other member, as designated by the chair, of the IRB or the Privacy Board, as applicable.

The following three criteria must be satisfied for an IRB or Privacy Board to approve a waiver of authorization under the Privacy Rule:

< The use or disclosure of protected health information involves no more than a minimal risk to the privacy of individuals, based on, at least, the presence of the following elements:
S an adequate plan to protect the identifiers from improper use and disclosure;
S an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law; and
S adequate written assurances that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of protected health information would be permitted by this subpart;
< The research could not practicably be conducted without the waiver or alteration; and
< The research could not practicably be conducted without access to and use of the protected health information.

- <u>Preparatory to Research</u>. Representations from the researcher, either in writing or orally, that the use or disclosure of the protected health information is solely to prepare a research protocol or for similar purposes preparatory to research, that the researcher will not remove any protected health information from the covered entity, *and* representation that protected health information for which access is sought is necessary for the research purpose. See 45 CFR 164.512(i)(1)(ii). This provision might be used, for example, to design a research study or to assess the feasibility of conducting a study.

- <u>Research on Protected Health Information of Decedents</u>. Representations from the researcher, either in writing or orally, that the use or disclosure being sought is solely for research on the protected health information of decedents, that the protected health information being sought is necessary for the research, *and*, at the request of the covered entity, documentation of the death of the individuals about whom information is being sought. See 45 CFR 164.512(i)(1)(iii).

- Limited Data Sets with a Data Use Agreement. A data use agreement entered into by both the covered entity and the researcher, pursuant to which the covered entity may disclose a limited data set to the researcher for research, public health, or healthcare operations. See 45 CFR 164.514(e). A limited data set excludes specified direct identifiers of the individual or of relatives, employers, or household members of the individual. Data use agreement must:

    < Establish the permitted uses and disclosures of the limited data set by the recipient, consistent with the purposes of the research, and which may not include any use or disclosure that would violate the Rule if done by the covered entity;
    < Limit who can use or receive data; and
    < Require the recipient to agree to the following:
        S Not to use or disclose the information other than as permitted by data use agreement or as otherwise required by law;
        S Use appropriate safeguards to prevent the use or disclosure of the information other than as provided for in data use agreement;
        S Report to the covered entity any use or disclosure of the information not provided for by data use agreement of which the recipient becomes aware;
        S Ensure that any agents, including a subcontractor, to whom the recipient provides the limited data set agrees to the same restrictions and conditions that apply to the recipient with respect to the limited data set; and
        S Not to identify the information or contact the individual.

Research Use/Disclosure With Individual Authorization. The Privacy Rule also permits covered entities to use or disclose protected health information for research purposes when a research participant authorizes the use or disclosure of information about him or herself. Today, for example, a research participant's authorization will typically be sought for most clinical trials and some records research. In this case, documentation of IRB or Privacy Board approval of a waiver of authorization is not required for the use or disclosure of protected health information.

To use or disclose protected health information with authorization by the research participant, the covered entity must obtain an authorization that satisfies the requirements of 45 CFR 164.508. The Privacy Rule has a general set of authorization requirements that apply to all uses and disclosures, including those for research purposes. However, several special provisions apply to research authorizations:

- Unlike other authorizations, an authorization for a research purpose may state that the authorization does not expire, that there is no expiration date or event, or that the authorization continues until the "end of the research study;" and

- An authorization for the use or disclosure of protected health information for research may be combined with a consent to participate in the research, or with any other legal permission related to the research study.

Accounting for Research Disclosures. In general, the Privacy Rule gives individuals the right to receive an accounting of certain disclosures of protected health information made by a covered entity. See 45 CFR 164.528. This accounting must include disclosures of protected health information that occurred during the six years prior to the individual's request for an accounting, or since the applicable compliance date (whichever is sooner), and must include specified information regarding each disclosure. A more general accounting is permitted for subsequent multiple disclosures to the same person or entity for a single purpose. See 45 CFR 164.528(b)(3). Among the types of disclosures that are exempt from this accounting requirement are:

- Research disclosures made pursuant to an individual's authorization;

- Disclosures of the limited data set to researchers with a data use agreement under 45 CFR 164.514(e).

In addition, for disclosures of protected health information for research purposes without the individual's authorization pursuant to 45 CFR164.512(i), and that involve at least 50 records, the Privacy Rule allows for a simplified accounting of such disclosures by covered entities.

Under this simplified accounting provision, covered entities may provide individuals with a list of all protocols for which the patient's protected health information may have been disclosed under 45 CFR 164.512(i), as well as the researcher's name and contact information. Other requirements related to this simplified accounting provision are found in 45 CFR 164.528(b)(4).

Transition Provisions. Under the Privacy Rule, a covered entity may use and disclose protected health information that was created or received for research, either before or after the compliance date, if the covered entity obtained any one of the following prior to the compliance date:

- An authorization or other express legal permission from an individual to use or disclose protected health information for the research;
- The informed consent of the individual to participate in the research; or
- A waiver of informed consent by an IRB in accordance with the Common Rule or an exception under FDA's human subject protection regulations at 21 CFR 50.24.

However, if a waiver of informed consent was obtained prior to the compliance date, but informed consent is subsequently sought after the compliance date, the covered entity must obtain the individual's authorization as required at 45 CFR 164.508. For example, if there was a temporary waiver of informed consent for emergency research under the FDA's human subject protection regulations, and informed consent was later sought after the compliance date, individual authorization would be required before the covered entity could use or disclose protected health information for the research after the waiver of informed consent was no longer valid.The Privacy Rule allows covered entities to rely on such express legal permission, informed consent, or IRB-approved waiver of informed consent, which they create or receive before the applicable compliance date, to use and disclose protected health information for specific research studies, as well as for future unspecified research that may be included in such permission.