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# HIV Risk Perceptions of HIV-Infected Adults Ages 30 to 49 Years in Atlanta, Georgia

Esther Nduta Mune-Ashford  
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# Walden University

College of Health Sciences

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Esther N. Mune-Ashford

has been found to be complete and satisfactory in all respects,  
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2016

Abstract

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in Atlanta, Georgia

by

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MPH, Walden University, 2012

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Minor, Southern Polytechnic State University, 2003

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

May 2016

## Abstract

More than 49,081 people were diagnosed with HIV in the United States in 2011. Of those 49,081 HIV-infected persons, 1 in 6 was not aware of being HIV positive. In 2011, Georgia had the 5<sup>th</sup> highest number of HIV diagnoses among the 50 U.S. states. This phenomenological study aimed to understand the lived experiences of HIV-infected adults, ages 30 to 49 years in Atlanta, Georgia, by understanding their perceptions of risk prior to contracting HIV. The health belief model was used to guide this study because it explains and predicts health-related behaviors and it has been used in previous studies to identify preventive behaviors specific to sexual behaviors. Purposive sampling was used to obtain 12 HIV-positive persons ages 30 to 49 years who lived in the metropolitan Atlanta area at the time of the study, were knowledgeable about HIV perceptions, and were able to discuss their lived experiences. Interviews were conducted to collect the data. The data analysis procedures included creating codes and categorizing the data, checking the validity of the codes, identifying patterns and themes, interpreting the data, and conducting member checks. Results showed that most participants did not perceive themselves to be at risk of HIV. Participants also experienced stigmatization and had challenges maintaining social relationships after their HIV positive diagnosis. Future priorities should focus on identifying best practices relevant to individual, familial, organizational, societal, environmental, economic, and policy factors to reduce the risk of HIV. This study is important for public health and social change because the findings might be used by healthcare professionals to identify and allocate the resources necessary to strengthen HIV/AIDS care and services to the populations who need them the most.

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## Dedication

This dissertation is dedicated to my only son, Brian Mune; my nephews, Andrew Mune Mbugua and Derrick Kairu Mbugua; my brother, Benjamin Mbugua Mune; my sister-in-law, Florence Wanjiku Kairu; my late father, John Francis Mune Mbugua; my late grandfather, Benjamin Mbugua Mune; and my late grandmother, Esther Nduta Mbugua.

Brian, your continued love, support, and understanding have brought me this far. I love you dearly, my son!

Andrew and Derrick, you have loved your auntie selflessly, and I forever owe you. You know that your auntie loves you dearly!

Benjamin Mbugua Mune, my dear brother, you have always been there for me through the good times and the hard times. You gave me my second life, and I would not have been able to complete my goals if it were not for you. I love you, Ben!

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Guka Benjamin Mbugua Mune, your belief in me when I was a little girl gave me the confidence to pursue my dreams.

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## Chapter 1: Introduction to the Study

### **Introduction**

Atlanta, Georgia ranked number one among all cities in the United States for new cases of HIV/AIDS in 2013 (Centers for Disease Control and Prevention [CDC], 2015a). In Atlanta, the continued high rates of HIV and HIV/AIDS infections are a major concern among stakeholders in the HIV epidemic. Data from the Georgia Department of Public Health (GDPH) indicated that Georgia ranked fourth in 2011 with new HIV diagnoses (GDPH, 2014). In 2012, Georgia had 50,436 HIV-infected persons; in 2005, it had 33,025 HIV-infected persons (GDPH, 2014). In order to understand why Atlanta continued to increase in alarming numbers of HIV cases, the main research question aimed to understand the lived experiences of HIV infected adults 30-49 years old with respect to their perceptions of risk prior to developing HIV infection. I conducted this study to understand the HIV risk perceptions among HIV-infected adults ages 30 to 49 years in Atlanta, Georgia.

In 2012, Georgians ages 30 to 39 years and 40 to 49 years accounted for the highest number of new HIV infections in the state (GDPH, 2014). There is a need to understand the HIV risk perceptions of HIV-infected adults ages 30 to 49 years old in Atlanta. The GDPH (2014) also reported that the prevalence of HIV is high in four counties in Georgia that are in close proximity to each other. Gwinnett, Fulton, Clayton, and DeKalb counties account for 60% of Georgia's HIV data, and all four counties are located within 187 square miles of downtown Atlanta (GDPH, 2014). For this reason, I focused on the HIV epidemic in the metropolitan Atlanta area. The higher annual rate of

infection within the four counties is caused by a high percentage of injection drug use (IDU), men who have sex with men (MSM), and poverty (Sullivan et al., 2014). I examined these main factors and their association to the perceptions of HIV risk among HIV-infected adults ages 30 to 49 years old in Atlanta, Georgia. This study provided awareness of the communities and regions in Georgia that are being affected the most by the high rates of HIV and HIV/AIDS infections.

### **Background of the Study**

It is important to understand the HIV epidemic by considering regional aspects of its prevalence, especially in regions such as the southeast, where HIV/AIDS presents disproportionately (CDC, 2012). The CDC reported in 2012 that nine of 19 Georgia public health districts had a high AIDS case rate that exceeded the national average. Surveillance data from the CDC showed that Georgia had the fifth highest number of HIV diagnoses among the 17 southern states in 2011. I focused my research on HIV-positive adults ages 30 to 49 years because this group represented the highest number of new HIV infections in Georgia in 2012 (GDPH, 2014).

Sullivan et al. (2014) investigated the ethnic and racial disparities that existed among White MSM and Black MSM to determine their impact on HIV prevalence and incidence rates in Atlanta, Georgia. The researchers recruited the same number of White MSM who were HIV-negative as the Black MSM who were also not HIV infected and used a comprehensive framework to identify the reasons for these disparities. Sullivan et al. found that the disparities affecting Black and White MSM in Atlanta were different from other demographic characteristics in the United States. Sullivan et al concluded that



the reasons were the result of multiple factors and that a multilevel framework was needed to understand the issue comprehensively.

Kalichman et al. (2010) recruited 344 men and women infected with HIV/AIDS who were living in Atlanta at the time of the study to examine how food insufficiency contributed to HIV-related health and treatment. Kalichman et al. found that 50% of the participants reported having a lack of sufficient food. Results also indicated that HIV/AIDS-infected persons who experienced food insufficiency also suffered from poor health, poor medication and treatment compliance, and higher HIV viral loads. Kalichman et al. concluded the persons infected with HIV/AIDS would benefit from programs that provided meals on a consistent basis.

The GDPH has been collecting and providing accurate records and data on HIV/AIDS since the early 1980s. As of December 31, 2003, Georgia law mandated the name-based reporting of HIV from all practitioners to the GDPH. I used Georgia's HIV/AIDS surveillance data for this study about HIV-positive persons and those who have progressed to AIDS (GDPH, 2014).

Carey et al. (2009) investigated the relationship between sociodemographic variables, sexual behaviors, and drugs and how they contributed to MSM having an increased rate of HIV infection. Carey et al. found that MSM who engaged in unprotected anal intercourse (UAI) were also frequent users of methamphetamines and Viagra. Carey et al. argued that MSM who participate in concomitant use of illicit drugs and unprotected sex should be provided with various HIV prevention interventions. Reif, Whetten, Wilson, and Gong (2011) reviewed epidemiological data and investigated HIV

incidence in the southern United States. They concluded that the high burden of HIV and the disproportionate impact of HIV in that part of the country was directly associated with socioeconomic factors. Reif et al. (2011) concluded that the southern states are affected by HIV more than other states are. However, Sullivan et al. (2014) reached a different conclusion and suggested that HIV rates in Atlanta, Georgia, are comparable to national rates of infection. Both Reif et al. and Sullivan et al. suggested that the HIV prevalence rates in Atlanta require a comprehensive approach to better understand the complex issues affecting HIV in the southern United States.

There are still gaps in knowledge about HIV infection and the disproportionate epidemic of HIV that continue to affect the southern States of the United States. According to Sullivan et al. (2014), MSM, poverty, and drug use are the main reasons for the high HIV infection rates in Atlanta. New HIV infections in Atlanta occur primarily among African Americans. Poverty, food insufficiency, homelessness, unprotected sex, incarceration, and injection drug use are other contributors to the high rate of HIV infections in Atlanta (Cairns, 2014). According to Cairns (2014), young Black men are the most severely burdened by HIV infections and AIDS diagnoses in Atlanta and often unaware of their personal risk for HIV. The HIV incidence rates (12.1% a year) among young Black MSM in Atlanta are one of the highest figures recorded in any single U.S. population cohort (Cairns, 2014).

The overall goal of this study was to understand how HIV-infected adults ages 30 to 49 years old perceived HIV risk prior to becoming infected. Because MSM is one of the main factors of the high prevalence rates of HIV infection in Atlanta, I examined the

HIV risk perceptions among MSM in Atlanta. Risk perception has been used previously to measure individuals' understanding of HIV infection (Cairns, 2014). Risk perception also has been applied in studies and used in various health intervention theories, such as the health belief model (HBM). Risk perception has been identified as a precursor to the adoption of protective behavior (Cairns, 2014). Even though MSM are the most affected by HIV infections, a huge knowledge gap exists regarding how members of this population perceive HIV risk. I sought to identify the factors influencing the HIV risk perceptions of MSM and IDUs and how poverty is associated with the high HIV prevalence rates in Atlanta. Poverty and injection drug use could interfere with HIV diagnosis and treatment (CDC, 2012). No study has been conducted to examine how MSM, poverty, and injection drug use influence the risk perceptions of HIV infected adults ages 30 to 49 years in Atlanta, Georgia.

### **Problem Statement**

The 3<sup>rd</sup> decade of the HIV/AIDS epidemic remains a significant problem for adults in the United States. More than 1.8 million people have tested positive for HIV, and there have been over 650,000 deaths from AIDS in the U.S since 1981 (Kates & Leggoe, 2005). According to the GDPH (2014), in 2011, Georgia ranked fourth in new HIV diagnoses; in 2010, Georgia ranked sixth for HIV incidence rates among adults and adolescents. In 2005, 33,025 people were living with HIV in Georgia, as compared to 50,436 in 2012 (GDPH, 2014). This was a 53% increase in the number of people living with HIV infections since 2005 in Georgia. There is a need to address the HIV problem in Georgia (Sullivan et al., 2014). According to the World Health Organization (WHO), a

generalized epidemic is a cluster greater than 1% (as cited in Rosenberg et al., 2014). In Georgia, four counties in close proximity to each other account for the highest number of HIV cases. All four counties are located within 187 square miles of downtown Atlanta, and the rate of HIV in the cluster is 1.34% (Rosenberg et al., 2014). The HIV prevalence in Georgia outside of the Atlanta cluster is 0.32% (Sullivan et al., 2014).

Among the 18 public health districts in Georgia, 60% of HIV cases are concentrated in Gwinnett, Fulton, Clayton, and DeKalb Counties (GDPH, 2014). As of 2012, DeKalb and Fulton Counties reported the highest numbers of HIV/AIDS cases in Georgia (GDPH, 2014). Fulton County reported 14,561 people living with HIV and 8,253 residents with AIDS in 2012 (GDPH, 2014). DeKalb County was the second highest, with 7,731 HIV-infected residents and 4,184 persons with AIDS (GDPH, 2014).

Poverty, injection drug use, and MSM have been acknowledged as the main factors leading to the higher annual rates of infection in the Atlanta HIV cluster (Sullivan et al., 2014). Other factors contributing to the higher annual rates of infection in the Atlanta HIV cluster include sex trafficking, HIV/AIDS-related stigma, and food insecurity (Sullivan et al., 2014). According to Dr. Armstrong, who oversees HIV/AIDS patients at the Grady Health Care HIV/AIDS treatment facility located in Atlanta, most HIV/AIDS patients are in a recurring lifestyle of disease, addiction, drugs, and homelessness (Karkaria, 2011).

According to the Medical Monitoring Project (MMP, GDPH, 2014), the top five unmet needs for HIV services in the state include assistance finding shelter/housing, meal or food service, and transportation. The MSM community represent 51% of Atlanta's

AIDS population, and 62% of MSM have reported having UAI and unprotected vaginal sex in 2010, while 38% used protection (GDPH, 2014). IDUs accounts for 16% of people with AIDS in Georgia (GDPH, 2014). In 2012, women represented 22% of new HIV diagnosis in Georgia, an increase of 19% since 1987 (GDPH, 2014).

In addition, the GDPH (2014) reported that Black women in Georgia represented 87% of individuals with AIDS; in 2011, Black males represented 78% of new HIV diagnoses in Georgia. The GDPH provides an annual state health profile report on the HIV/AIDS epidemic that includes estimated numbers of HIV diagnoses by age, transmission category, and race and ethnicity. In 2012, Black people accounted for 29% of Georgia's population but 63% of current AIDS cases and 77% of new AIDS cases in Georgia. I targeted adults ages 30 to 49 years because they accounted for the highest number of HIV cases in 2012 for males and females in Georgia (GDPH, 2014).

I conducted this study to address the need to understand the HIV risk perceptions of HIV-infected adults ages 30 to 49 years old in Atlanta. In Atlanta, HIV/AIDS is the highest in the inner-city area. No other studies have been conducted on the lived experiences of HIV-infected adults ages 30 to 49 years in metropolitan Atlanta, and no phenomenological studies have investigated the perceptions of HIV-infected persons in Atlanta before they contracted the virus. According to the CDC (2012), it is important to understand the HIV epidemic by considering regional aspects of the infection, especially in areas that have high rates of HIV/AIDS. The Atlanta metropolitan area is an example of an inner-city area with a HIV epidemic focus because it has one of the most intense epidemics in the country.

### **Purpose of the Study**

The purpose of this phenomenological study was to understand the lived experiences of HIV-infected adults ages 30 to 49 years in Atlanta, Georgia, by gaining their perceptions of risk prior to contracting HIV. Qualitative studies serve the purpose of understanding and explaining participant meaning (Creswell, 2013). According to Creswell (2013), qualitative research is the in-depth examination of phenomena that helps to answer complex questions. I used a phenomenological approach to obtain the perceptions of a sample of HIV-infected adults. After conducting interviews with the participants, I produced the findings according to their perspectives by using verbatim quotations that were textual representatives of the participants' own voice to provide deeper understanding (Creswell, 2013). The results could help to inform local and international public health researchers, suggest new research for future HIV/AIDS prevention and intervention program planning, and develop new models and theories. The findings also have important implications for future HIV interventions.

### **Research Question**

The study was guided by one research question (RQ): What are the lived experiences of HIV-infected adults ages 30 to 49 years with respect to their perceptions of risk prior to developing HIV infection?

### **Conceptual Framework**

I conducted this study to understand the lived experiences and HIV risk perceptions of adults ages 30 to 49 years who were living in Atlanta at the time of the study. At the start of any research, the researcher must consider the applicable theory that

provides a solid foundation and basis of knowledge of the phenomenon being investigated (Creswell, 2013). I determined that the HBM, which posits that beliefs and attitude guide behavior (Glanz, Rimer, & Viswanath, 2008), was the most applicable model for this study. The HBM influenced how evidence was collected, analyzed, interpreted, and used in this study (Creswell, 2013).

The role of the HBM was vital to this study because theories are at the heart of practice, planning, and research in public health (Glanz et al., 2008). Knowing the role of theory during the literature review process helped me to understand the specific application to the HIV epidemic. Having a poor understanding of the role of theory such as HBM could have negatively affected the results because of the poor identification and description of the issue under investigation (Glanz et al., 2008). According to Glanz and Bishop (2010), it is necessary to read and understand the HBM theory before applying it to research.

The HBM was the most appropriate model to use in this study to understand the HIV risk perceptions among HIV-infected adults ages 30 to 49 years living in Atlanta at the time of the study because it explained behavioral changes according to personal perceptions of health beliefs and attitudes (Glanz et al., 2008). The HBM has previously been applied in addressing high-risk short-term and long-term sexual behaviors that can lead to HIV infection (Glanz et al., 2008).

All six constructs of the HBM were aligned with the RQ:

1. Perceived risk (perceived vulnerability to HIV infection).
2. Perceived severity (perceptions about the seriousness of contracting HIV).

3. Perceived benefits (perceptions of the benefits in reducing HIV risk).
4. Perceived barriers (perceptions of the challenges to taking preventive measures).
5. Cues to action (plans or strategies to act on advised preventive action).
6. Self-efficacy (belief in the ability to take action and perform the prescribed action).

The HBM also was aligned with the significance of the study:

1. Perceived risk (“I can get infected with HIV”).
2. Perceived seriousness (“HIV/AIDS has caused death, and it could shorten my life if I got infected”).
3. Perceived benefits (“I will reduce my risk of HIV infection if I use condoms every time I have sex”).
4. Barriers to taking action (“Condoms are very expensive, and I do not have money to afford them”).
5. Cues to action (“I will use reminder messages such as ‘no glove, no love’ before sex”).
6. Self-efficacy (“I will correctly use condoms to protect myself from HIV infection”).

### **Nature of the Study**

This study was based upon a qualitative method of inquiry. Qualitative research seeks to understand the RQ based upon the perspectives of the participants (Creswell, 2013). Qualitative methods provide a more in-depth meaning and understanding of



people's perceptions and interpretations by the use of open-ended interview questions (Creswell, 2013). The primary data collection instrument in qualitative studies is the researcher (Creswell, 2013). During the data collection process, experiential knowledge is required from participants under natural conditions, and definitions of the variables emerge from the respondents (Creswell, 2013).

I conducted interviews to inform the reader of the phenomenon under investigation. The interview questions began with words such as "what" or "how" to allow the respondents to more fully describe their risk perceptions of HIV (Creswell, 2013). The size of the sample was guided by the point of saturation, meaning that the sample had to be large enough to uncover all valuable perceptions (Creswell, 2013).

I followed a phenomenological approach to understand how a sample of HIV-infected adults perceived HIV risks prior to contracting the infection and to explore the participants' lived experiences after contracting HIV infection in Atlanta. As a phenomenological researcher, I wanted to obtain the participants' descriptions of the lived experience, including feelings (e.g., sadness, loneliness, fear, hopelessness, grief, and despair); memories; and thoughts (Creswell, 2013). I asked open-ended interview questions to elicit more information from the participants about the perceived HIV risks. For example, I asked them to "describe how you perceived the use of condoms before learning you were HIV positive." Permission to use established interview items was granted by Nwankwo (2014; see Appendix A).

### **Definitions of Terms**

*African American and Black:* The terms African American and Black were used interchangeably in the study. For the purpose of this study, the term *African American* referred to Black persons born in the United States, and the term *Black* was used to include individuals such as Black immigrants, who might have been Black persons of any foreign country outside of the United States now residing in the United States.

*HIV:* HIV is a disease that is transmitted sexually and comprises viruses that damage CD4 blood cells and the body's immune system. A CD4 count higher than 500 is HIV Stage 1, a CD4 count of 200 to 499 is HIV Stages 2 and 3, and a CD4 count less than 200 is full-blown AIDS (GDPH, 2014). Having unprotected sex with HIV-positive persons can lead to HIV infection because infected vaginal secretions, blood, and semen can enter the body.

Another common way of HIV transmission is needle sharing when using drugs with HIV-infected persons. Other methods of HIV transmission that were beyond the scope of this study were blood transfusions and infection through pregnancy, delivery, or breast feeding. Individuals who have AIDS are considered to be at the most advanced stage of HIV infection and cannot fight the infection because their immune systems have been compromised. At the AIDS stage, the infected individuals might develop tumors and opportunistic infections (GDPH, 2014).

*HIV epidemic:* HIV epidemic refers to the spread of HIV in specific locations within particular time frames and affecting many people at the same time (CDC, 2013).

*HIV-infected persons:* The HIV-infected persons in this study were Georgia residents at the time of the study, even if their diagnoses had been made out of state. New HIV diagnoses were persons who were residents in Georgia at the time of confirmation of their positive HIV status (GDPH, 2014).

*Southern states:* Southern states were defined according to the U.S. Census Bureau (2012) as Georgia, South Carolina, Tennessee, Maryland, Texas, Alabama, Virginia, Delaware, West Virginia, Arkansas, Oklahoma, North Carolina, District of Columbia, Mississippi, Florida, Kentucky, and Louisiana.

*Targeted southern states:* The targeted southern states were Georgia, Texas, Florida, Louisiana, South Carolina, North Carolina, Tennessee, Mississippi, Florida, Kentucky, Oklahoma, and Louisiana. Some of the highest ranking regions in the south for HIV infections per 100,000 people in 2013 included Atlanta, Georgia; Memphis, Tennessee; Miami, Florida; and Baltimore, Maryland (CDC, 2014b).

### **Assumptions**

I assumed that the research instruments used were the most appropriate to collect the data and answer the RQ. I assumed that the participants would share their HIV risk perceptions. I assumed that the sample was representative of the target population. I assumed that the participants would answer the interview questions honestly and provide information about their HIV risk perceptions before and after diagnosis. I assumed that a participant's personal identity would remain anonymous and their responses would be private and confidentially preserved. I also assumed that the findings would support future research and preventive measures targeting the study population.

### **Scope and Delimitations**

This study was limited to adults ages 30 to 49 years who were residing in Atlanta, Georgia, at the time of the study. This age range was chosen because in 2012, males and females in this age group had the highest HIV incidence rate in Georgia (GDPH, 2014). The study also was limited to the metropolitan Atlanta area because the prevalence of HIV infections in Georgia lies in a cluster of four counties that fall within an area of approximately 187 square miles in metropolitan Atlanta. Hence, the findings might not be generalized to other HIV-infected adults in other U.S. states. A phenomenology framework was chosen for this qualitative study to answer the RQ and help to understand how the participants perceived the risk of HIV infection.

### **Limitations**

This study was limited to a phenomenological approach, so I used interviews as the main data collection method. The validity of the data collection method could have been challenged because the results were dependent on the honesty of the participants and the accuracy of the information shared during the interviews. The interviews were unstructured and were guided by the respondents' answers.

Another limitation was related to the nature of self-reporting. Data that are self-reported can have potential biases that can influence the results. A tape recorder was used to record the data. Participants were informed that they were free to answer all questions or stop at any time. During the consent process, participants were advised that the interview process could take more than 30 minutes. This information gave them the opportunity to plan their time accordingly before the initial interview.

### **Significance of the Study**

I sought to understand the HIV perceptions of adults ages 30 to 49 years who were living in Atlanta at the time of the study about their risk of HIV infection prior to contracting the infection and their subsequent lived experiences after contracting HIV. The importance of this study to the public health field is the identification of the HIV risk perceptions of HIV-infected adults prior to developing HIV and their lived experiences after becoming HIV positive. No other phenomenology study has been conducted on this topic. This study could provide insight into perceptions, beliefs, and attitudes of HIV infection and transmission. The HBM was used to understand how adults ages 30 to 49 years who were living in Atlanta at the time of the study perceived their risk of getting infected with HIV, perceived that the severity and consequences of being HIV positive was worth avoiding, perceived that the recommended health action required to reduce the severity was worth the effort of changing their behavior. HBM was also used as a lens to understand that adults ages 30 to 49 years in Atlanta perceived that they have the functional self-confidence to change their behavior. Cues to action is one of the HBM constructs that is applicable to all other stages. Examples of cues to action include a health education message in the form of a poster or a one-on-one conversation between an HIV infected person and a health professional.

The study also could provide deeper insight and understanding about why Atlanta continues to have an increase in the number of new HIV diagnoses (GDPH, 2014). According to the CDC (2012), it is important to know the regions with high rates of HIV to facilitate the proper allocation of resources to those areas that are the most affected

(CDC, 2012). According to the MMP 2010 Fact Sheet (GDPH, 2014), by identifying the unmet needs and the specific population most affected, the findings could help to provide levels of support in such areas as health insurance, sex education, drug prevention services, HIV prevention strategies, food services, shelter, and transportation.

### **Social Change Implications**

The findings could help to identify new HIV prevention measures in relation to infection, morbidity, and mortality. These prevention and intervention strategies might increase the health and well-being of HIV-infected individuals across the United States. The findings also might benefit other researchers, who could use them as a guide to study the HIV/AIDS epidemic in various local and global geographic locations.

It is vital to understand and document the factors contributing to the lack of race/ethnicity data in HIV reports (GDPH, 2014). The findings could strengthen the knowledge base of HIV caregivers and service providers, provide insight into HIV prevention measures, improve the health education of individuals infected with HIV/AIDS persons as well as the general population, and improve client-caregiver relationships. This study has the opportunity to contribute to current knowledge about issues influencing HIV infection, diagnosis, and care in Atlanta, Georgia. When the general public become more aware of a public health issue, individuals, organizations, the private sector, and government agencies are more likely to respond by providing funding and resources to strengthen the health care system and expand services such as health education programs to the population in need (CDC, 2015b). The results also could encourage more research on the factors contributing to the increased incidence of

HIV/AIDS. The findings could contribute to positive social change. Public health professionals could use the results to plan, promote, implement, and evaluate HIV prevention and intervention programs. Policymakers could use the findings to advocate for additional services and resources for HIV-infected populations.

### **Summary**

According to the CDC (2015a) HIV surveillance report, Atlanta ranked number one among U.S. cities in new HIV diagnosis in 2014. In 2013, Atlanta ranked number five in new HIV diagnosis among U.S. cities. The high increase in new HIV diagnosis from 2013 to 2014 indicates that Atlanta continues to contain a disproportionately higher number of new HIV infections compared to other regions in the U.S. As of 2013, there were 447,841 people living in the metro Atlanta area. In 2013, Fulton County ranked number one among Georgia counties with 14,695 people who were HIV positive. DeKalb County came second with 6,116 HIV positive people in 2013. According to GDPH (2015), in 2013, Fulton and DeKalb Counties also had the highest cases of new HIV diagnoses among other counties in Georgia. Fulton had 667 and DeKalb had 414 of new HIV diagnoses per 100,000 people in Georgia. The high HIV/AIDS incidence rates remain a significant problem in Atlanta. Characteristics such as MSM, high poverty levels, and injection drug use provided insight into the high rates of HIV infection in metropolitan Atlanta (Sullivan et al., 2014). A combination of interrelated social and economic factors has contributed to the HIV rates in Atlanta: lack of public benefits, lack of shelter/housing, insufficient meal or food services, food insecurity, lack of

transportation assistance, sex trafficking, and continued HIV/AIDS-related stigma (GDPH, 2014; Sullivan et al., 2014).

I sought to understand the HIV risk perceptions of a sample of HIV-infected adults ages 30 to 49 years in Atlanta, Georgia, prior to their contracting the infection. This study was needed because no other researchers had investigated these perceptions. A phenomenological approach allowed me to collect in-depth information using an interview protocol from the perspectives of the participant (Creswell, 2009). The HBM served as the theoretical foundation of the study. I chose the HBM because it had been used successfully in previous studies related to health perceptions (Glanz et al., 2008).



## Chapter 2: Literature Review

### **Introduction**

Scientific research on HIV, treatment, cure, and progression to AIDS has been documented in peer-reviewed journals. However, no researchers have investigated the perceptions of adults in Atlanta, Georgia, of their HIV risk prior to becoming infected and their lived experiences after contracting HIV. I conducted this literature review to provide comprehensive information about previous research related to HIV/AIDS and to further the current understanding of the perceptions of HIV risk among HIV-infected adults ages 30 to 49 years in Atlanta, Georgia. According to the CDC (2012), it is important to consider the regional aspects of the HIV epidemic, particularly in areas where HIV diagnoses have been high and are continuing to increase.

In this literature review, I discuss the problem being investigated, identify the research topic, describe similar studies supporting the research topic, discuss the gap in literature and knowledge, and present the key search terms and literature search strategies used. The literature review summarizes previous studies that addressed the environmental, social, cultural, and behavioral factors contributing to the high incidence of HIV. The literature review also covers other related factors, including homelessness, food insecurity, HIV-associated health risk behaviors, sex trafficking, race/ethnicity and gender issues, HIV/AIDS-related stigma, personal beliefs, availability of care for HIV-infected people, care priorities of HIV-infected adults, and cost of HIV/AIDS in Atlanta.

Finally, the HBM is reviewed and discussed as the theoretical framework used in this study. Chapter 2 ends with a summary from the literature review findings regarding lived experiences, HIV risk perceptions, and prevention efforts.

### **Literature Search Strategy**

I searched the Cochrane Database of Systematic Reviews, MEDLINE, Google, EBSCO, Sage, CINAHL, PubMed, the *American Journal of Public Health*, the GDPH website, and CDC websites for relevant information. These peer-reviewed, evidence-based primary studies were used to review the literature and to ensure the credibility of the study.

Key words and specific search terms used included the following: *HIV in Atlanta, HIV in Georgia, HIV demographics, HIV and perceptions, HIV and poverty, HIV and homelessness, HIV and food insecurity, HIV-associated health risk behaviors, sex trafficking and HIV, HIV/AIDS-related stigma, HIV personal beliefs, availability of care for HIV-infected people in Atlanta, cost of HIV/AIDS in Atlanta, MSM, HIV perceptions, poverty and HIV/AIDS, race and HIV, HIV and stigma, HIV and age, unsafe sex, sexual beliefs of HIV, HIV protection, HIV/AIDS persons and care priorities, HIV risk behaviors, condom use, and HBM.*

### **Literature Review**

#### **Demographic and Social Settings of HIV**

Reif et al. (2011) selected a few southern states to investigate HIV. They focused on several southern states on the basis that they had been more impacted by the HIV epidemic than other U.S. states. All of the states in their study also shared common

HIV/AIDS characteristics, one of which was high poverty rates. Reif et al. (2011) used HIV epidemiological and outcomes data from the CDC surveillance statistics and other data sources to investigate new HIV infections and morbidity in the metropolitan areas of the targeted states. They concluded that the southern states continued to have a high incidence of HIV and that metropolitan areas had disproportionately been affected by the HIV epidemic.

Similar to Reif et al.'s (2011) study, Aral, O'Leary, and Baker (2006) also conducted an overview of the incidence of HIV in the southern U.S. states. They found that the number of individuals or groups of persons who are connected to one another sexually (i.e., through sexual networks) can determine the rate of HIV spread within specific communities. Therefore, understanding the nature of sexual networks can help to explain why specific populations continue to be affected by the HIV epidemic more than others are. Aral et al. also found that the epidemiology of HIV is influenced by a combination of economic, demographic, and social factors. Aral et al. further noted that the high levels of poverty and the competition for limited resources in the southern U.S. states make it difficult for them to provide sufficient HIV/AIDS health care services. Unlike Reif et al., Aral et al. concluded that the incidence of HIV and other STDs has declined in the southern states and other areas of the United States. Aral et al. also identified a wide gap in research about the epidemiology of HIV and other STDs.

Rencher (2012) investigated the relationship between mobility and HIV incidence rates in 10 high-prevalence zip codes in Atlanta, Georgia. Rencher conducted the study with 927 adults, of whom 479 (52.5%) were men and 433 (47.5%) were women. Of the

927 participants, 49 respondents (5.3%) were HIV positive, and 878 (94.7%) were HIV negative. The sample comprised nine non-Hispanic Whites (0.97%), 903 non-Hispanic Blacks (97.41%), six Hispanic Americans (0.65%), and nine of other racial backgrounds (0.97%). The participants mean age was 36.2 ( $SD = 12.9$ ). The participants were almost evenly distributed in four age group quartiles: 252 (27.2%) between 18 and 24 years, 217 (23.4%) between 25 and 36 years, 244 (26.3%) between 37 and 47 years, and 214 (23.1%) 48 years or over. The number of heterosexual participants was 799 (86.3%); those identifying as gay, lesbian, or bisexual numbered 110 (11.9%); and transgender, transsexual, and others numbered 17 (1.8%). The education level of participants was as follows: 427 (46.0%) were not high school educated, 363 (39.2%) had graduated high school, and 137 (14.8%) reported some college or higher. Rencher concluded that mobility in the inner-city neighborhoods could not be separated from the demographic and behavioral characteristics that defined the population.

Rencher (2012) found that the men in the study who used public transportation were significantly at less risk of contracting HIV than men who used private or personal public transportation. Rencher also found that the women in the study who used any private car were significantly at less risk than women who used public transportation of contracting HIV. Rencher concluded that mobility and a cluster of several other factors that occurred together contributed to the high prevalence rates of HIV in inner-city neighborhoods.

Hixson, Omer, del Rio, and Frew (2011) examined the association between clustering and HIV prevalence rates in Atlanta. Hixson et al. identified cluster

characteristics by calculating the average travel time to access local services that had free HIV screening and intervention services. They concluded that a high poverty rate, MSM, and injection drug use were the main factors contributing to the HIV epidemic in Atlanta. Hixson et al. also concluded that there was an HIV cluster in Atlanta because HIV-infected adults were living in specific metropolitan areas.

Rothenberg (1983) conducted an early investigation into the relationship between social networks and HIV risk behaviors. Rothenberg conducted a longitudinal study and interviewed 228 IDUs and other persons who were engaging in other HIV risk behaviors in six metropolitan Atlanta communities. Rothenberg interviewed the participants and followed up with them every 6 months for 2 years. The interviews focused on HIV risk behavior factors such as the use of illicit drugs and participation in sexual networks. Rothenberg's results indicated that the concentration of poverty, injection drug use, MSM, and the increased rates of HIV-positive sexual partnerships contributed to an increased risk of HIV infection.

### **Poverty and HIV**

Reif et al. (2011) examined the rates of poverty in different regions within the United States and found that the southern states accounted for 21% of the national poverty rate. Western states were next at 19.7%, followed by northeastern states at 16.5%. Georgia was among the states with the highest poverty levels (21.0%) and uninsured individuals (19%). Reif et al. also noted that the southern states had low educational national averages, most school children were from low-income families, and the majority of children attending public school accounted for the highest dropout rates.

Reif et al. also found that the incidence rates of HIV were concentrated in Georgia counties that had high poverty rates. Reif et al. concluded that poverty is a factor directly related to the lack of education and poorer HIV health status in the southern states.

Vogenthaler et al. (2013) conducted a study to understand how food insecurity was associated with HIV risk behaviors. A total of 154 HIV-infected participants who were housed in homeless shelters in the San Francisco area participated in the study. Vogenthaler et al. found that food insecurity was directly related to the risk of contracting HIV. Vogenthaler et al. also concluded that food insecurity was a contributor to decreased HIV treatment compliance. Vogenthaler et al. suggested that researchers should conduct further studies aimed to how food insecurity contributes to increased HIV transmission and lack of treatment.

Wang et al. (2011) aimed to understand the relationship between food insecurity and HIV. Their cross-sectional study focused on such factors as HIV risk, transmission, and treatment among HIV-positive patients receiving treatment in the United States. Wang et al. compared food-secure participants to those who reported food insecurity, a term that they defined based upon participants' statements that they feared not having sufficient food for themselves and their families over the previous 30 days. Results showed that antiretroviral therapy (ART) was not effective in suppressing viral loads on HIV-infected participants who reported food insecurity. Wang et al. concluded that food insecurity can directly interfere with HIV treatment and care.

Vogenthaler et al. (2013) and Wang et al. (2011) investigated the relationship between food insecurity and HIV care among HIV-infected persons. Vogenthaler et al.

concluded that reducing food insecurity might decrease the incidence rates of HIV, whereas Wang et al. concluded that food insecurity is an independent factor not directly related to HIV transmission. Vogenthaler et al. and Wang et al. both suggested that more longitudinal studies be conducted to investigate the potential causal association between food insecurity and HIV treatment and outcomes.

Kalichman et al. (2010) investigated the ways in which food insecurity affected HIV/AIDS treatment in Atlanta, Georgia. They focused on food insecurity and poor nutrition as factors contributing to low adherence to treatment protocols and the poor health status among HIV individuals, households, and communities in Atlanta, Georgia. Kalichman et al. found that 50% of the study participants reported a lack of sufficient food in their households. They concluded that this lack of food security contributed to the faster progression of HIV to AIDS. Kalichman et al. further noted that the lack of proper nutrition was associated with ART noncompliance. Kalichman et al. identified a need for more HIV/AIDS interventions providing consistent food services.

Kalichman et al. (2012) investigated the health and social service that were available for people living with HIV (PLWH) in Atlanta. Participants were 5,489 men and 5,165 women LWH in Atlanta. Kalichman et al. used a questionnaire to inquire about the type of health services that the participants had access to in Atlanta. More than 60% of the participants reported experiencing hunger, and the majority of participants reported not being able to access HIV services.

Kalichman et al. (2012) found that the women's lack of access to HIV services and noncompliance with HIV treatment were associated with depression. Unlike the

women, the men in the study associated their failure to access services with higher CD4+ T cell counts, high alcohol use, and depression. The men as well as the women reported depression as a common factor related to their lack of access to HIV services and care. Contrary to Wang et al. (2011), who concluded that food insecurity was not directly associated with low CD4 counts or progression to AIDS, Kalichman et al. concluded that the lack of proper nutrition was directly associated with low the CD4+ T cell counts of HIV-positive men and that food insecurity negatively interfered with access to HIV/AIDS services and care.

Shacham, Lian, Önen, Donovan, and Overton (2013) investigated the association between high-risk sexual behaviors, neighborhood characteristics, and HIV interventions. One of the study objectives was to determine whether low-socioeconomic status (SES) neighborhoods were more likely to experience HIV clustering. To understand how lower SES and other neighborhood factors could affect HIV status and care, Shacham et al. performed behavioral assessments on 762 HIV-positive men and women who visited HIV outpatient clinics in the St Louis metropolitan area. Shacham et al. concluded that the individuals from a lower SES were impacted by HIV at a disproportionately higher rate. Shacham et al. suggested that increasing the resources and interventions in low-SES neighborhoods would increase HIV treatment options and provide better management of the progression of HIV to AIDS.

Shacham et al.'s (2013) results were consistent with the earlier conclusions of other researchers. For example, Hixson et al. (2011) and Rencher (2012) examined the prevalence of HIV cases in Atlanta, Georgia, in relation to population characteristics.



Both sets of researchers concluded that the concentration of poverty contributed to the spread of HIV and increased the risk of infection for individuals living in inner-city areas, regardless of their involvement or noninvolvement in risky behaviors. Kalichman et al. (2010) investigated the impact of food insufficiency on individuals with HIV/AIDS in Atlanta, Georgia. Kalichman et al., Shacham et al., Rencher, and Hixson et al. concluded that people from a low-SES background are more likely to be negatively impacted by HIV/AIDS because the incidence of infection is more pronounced in poor inner-city areas.

### **Injection Drug Use and HIV Infection**

According to CDC (2014b) HIV surveillance data, approximately 184,673 AIDS persons who also were IDUs have died since 1982. An estimated 3,723 IDUs who also had a diagnosis of AIDS died in 2011. Injection drug use has been identified as a HIV risk factor in the United States and continues to account for approximately 10% of new HIV infections annually. In 2010, IDUs accounted for 8% of HIV cases in the U.S. In 2011, IDUs accounted for 15% of HIV-positive persons in the U.S. In 2010, 16% of women who were HIV-positive the U.S were IDUs (CDC, 2014b). Injection drug use has been identified as one of the major contributing factors to the high incidence of HIV among women. According to the CDC, MSM represented the highest risk factor for the incidence of HIV incidence, followed by opposite sex contact and injection drug use.

According to the GDPH (2014), IDUs accounted for 16% of AIDS cases in Georgia. The GDPH collaborated with the CDC and Emory University to monitor HIV risk behaviors in the metropolitan Atlanta area. This tripartite HIV surveillance group

focused on three populations in the Atlanta area identified as being at high risk of contracting HIV: MSM, IDUs, and heterosexuals. The CDC, Emory University, and the GDPH conduct an annual surveillance of these three populations. The GDPH also collects data every 3 years from injection drug use HIV risk populations in the Atlanta metropolitan statistical area.

The GDPH collected data between September and December of 2009 for the second injection drug use cycle (GDPH, 2014). The GDPH recruited 466 IDUs (380 men [82%], 80 women [17%], and six transgender [1%]) between the ages of 19 and 70 years through a respondent-driven sampling methodology. The mean age in the second injection drug use cycle was 47 years. Participants were living in Atlanta. All 466 participants performed HIV screening and completed interviews. Most of the participants were Black IDUs.

The interview survey results from the GDPH in 2009 (GDPH, 2014) revealed that 72% of the study participants were high school educated; 80% reported being homeless in the past; and 77% were currently homeless. Results showed that the injection drug use population reported sharing syringes (34%) and other paraphernalia (80%). The injection drug use of choice associated with HIV was 60% heroin injecting, 16% combination of heroin and powdered cocaine injecting, 15% crack cocaine injecting, and 8% crystal meth injecting. Participants also reported injection drug use-sharing networks. More than 69% of the IDUs did not know their injection drug use partners' HIV status, and 32% shared injected drugs with MSM partners. The second injection drug use cycle results also showed that 87 of the 466 participants were HIV positive.

Khan et al. (2013) investigated the HIV/STD risk factors in relation to non-injection drug use and injection use of crack cocaine among young adults ages 18 to 28 years in the U.S. Khan et al. used secondary data from an adolescent health study to obtain data on the participants' SES factors in the first wave of the study. During the third wave, Khan et al. interviewed the respondents again about their sexual risk behaviors and drug use habits. Measures used included interview questions about exposure to different types of crack cocaine drug use. Results showed that young adults who used injections for crack cocaine use were at equal risk as those who used non-injection methods. Khan et al. concluded that the literature has failed to address the extensive impact of injection drug use as a cause of the high incidence of HIV.

Khan et al.'s earlier findings (2013) were consistent with those of the GDPH in 2014. Both found that injection drug use elevated the risk of HIV infection. Both found that sexual risk behaviors and sharing needles were major contributors to the increase of HIV. Both concluded that demographics such as geographic location, race, gender, and education were important factors for HIV risk in populations that used illicit drugs.

Lichtenstein (2007) examined how the use of illicit drugs contributed to HIV/AIDS disparities in the incidence rates in Alabama. Lichtenstein triangulated published research and HIV surveillance systems from the local and national levels to understand the relationship between the social environment and the use of illegal drugs related to the incidence of HIV/AIDS in Alabama's Black Belt region. Lichtenstein found that HIV/AIDS was concentrated in specific geographic boundaries and that rural areas of Alabama were experiencing the highest impact of HIV/AIDS more so than other states

were. Lichtenstein concluded that the lack of socioeconomic resources, high levels of poverty, poor health infrastructure, and racial health disparities in the Black Belt region of Alabama were contributing to the HIV risk and low life expectancy.

Sterk (2002) conducted an intervention on HIV risk among black women in Atlanta, Georgia, between the ages of 19 and 44 years who were using crack cocaine. The intervention focused mainly on reducing the risk of HIV among women in their social relationships and in the larger community context of their neighborhoods. Sterk conducted interviews with a sample of women in Atlanta who were using crack cocaine. The model consisted of a formative research phase followed by two interventions, a motivational intervention, and a negotiation intervention. Other than focusing on who the women were, the model emphasized what the women did, where they did it, their personal lived experiences with HIV, and their vulnerabilities and strengths. One-on-one interventions were planned to address the goals of each of the women, who were taught different approaches to make behavioral changes, identify goals, and solve problems. Sterk used the intervention approach because it had been successful in prior health interventions related to injection drug use and HIV risk reduction strategies.

Sterk (2002) found that the African American women in this intervention had experienced sexual abuse and trauma and had been engaged in the sex trade. Sterk also found that the women wanted to practice health behaviors that would help them to reduce their drug use and risk of HIV/AIDS infection. Sterk concluded that cultural, racial, and ethnic factors should be considered when developing HIV/AIDS health intervention

programs. Sterk asserted that HIV prevention and intervention efforts should focus on multiple, not single, risks.

Sterk (2002) also suggested that future researchers study the impact of community factors to gain more insight into HIV risk factors. Likewise, Lichtenstein (2007) stated that social factors, geographic locations, race, and ethnicity must be incorporated when developing HIV preventive approaches associated with illicit drug use. Suggestions made by Lichtenstein and Sterk were consistent with the later conclusions of Khan et al. (2013) that prevention and intervention efforts also must consider community-level factors.

### **Men Who Have Sex With Men**

MSM, regardless of race or national origin, are impacted by HIV/AIDS more than any other U.S. population, and approximately 885 MSM have died of AIDS since 1982 (CDC, 2014a). According to the CDC (2014a), there were 5,302 deaths of MSM who had been diagnosed with AIDS in 2011. In 2008, the incidence of HIV among MSM was 26,700; it was 29,800 in 2010 (CDC, 2014a). The difference between 2008 and 2010 indicated a significant 12% increase among MSM. Even though MSM represented only 4% of the male U.S. population in 2010, they carried the burden of a 78% of HIV incidence rate. In 2010, MSM in the United States represented 63% of new HIV diagnoses. In 2011, 54% of the U.S. population diagnosed with HIV comprised MSM (CDC, 2014a).

By race, the CDC (2014a) reported White MSM to be the most impacted (11,200) by new HIV infections in 2010. By transmission, Black MSM were the second most impacted (10,600) by HIV in 2010. By age, Black MSM whose ages ranged between 13

to 24 in 2010 represented the highest HIV rates (4,800) when compared to all other races. Black young MSM have been the most affected by HIV infection of any other age group or HIV risk population. Young Black MSM represent over 50% of new HIV cases in United States (CDC, 2014a).

Sullivan et al. (2014) investigated racial disparities between White and Black MSM in relation to HIV/STD. They used online samples from the self-selected databases to recruit 454 Black and 349 White men between July 2010 and December 2012. The participants performed HIV and STD screening, provided demographic information, disclosed histories of sexual partners, and completed a survey measuring their sexual behaviors (Sullivan et al., 2014). The online survey results showed that Black MSM were more impacted by HIV (43%) than White MSM (13%). The results also showed that more young Black MSM experienced higher unemployment rates, were less educated, have fewer anal sex partners, be bisexual, have less UAI with partners, and have less non-injection drug use compared to their White counterparts. Even though the Black MSM had lower HIV diagnosis rates, they reported more rates of rectal chlamydia and gonorrhea than White MSM. The Black MSM reported having more casual sex partners than the White MSM, and they also were less likely to disclose their serostatus. Sullivan et al. concluded that racial and ethnic disparities existed at the individual, social, and community levels between White and Black MSM in relation to HIV/STD prevalence rates in Atlanta. Sullivan et al. suggested the need for a framework of individual, community, societal, and environmental levels to understand the complexity of HIV and racial disparities.

Peterson and Jones (2009) reviewed secondary data to understand the social and structural factors that contributed to Black MSM being at a high risk for HIV. Peterson and Jones described the impact of HIV/AIDS in the U.S. has disproportionately affected Black MSM. Peterson and Jones (2009) sought ways to effectively develop HIV preventive intervention measures for the Black MSM population. According to Peterson and Jones, in comparison to other races, Black MSM are the most affected by HIV/AIDS. A detailed review of the social, environmental, and organizational aspects contributing to this prevalence found that young Black MSM ages 15 to 22 years and Black adult MSM ages 23 to 49 years in the United States were affected excessively by HIV/AIDS. Peterson and Jones suggested that research and structural interventions focus on HIV prevention among Black MSM.

### **HIV-Associated Health Risk Behaviors**

The CDC (2014b) defined HIV sex risk behaviors as actions that can increase HIV transmission rates. For example, reported sexual risk behaviors among MSM include having UAI, having multiple sexual partners, not disclosing seropositive status to sex partners who are at risk of HIV infection, and having sex while under the influence of injection drug use (CDC, 2014b; Sullivan et al., 2014). Sexual risk behaviors can increase the risk of HIV infection and transmission as well as other STDs (CDC, 2014b).

The GDCPH (2014) investigated the prevention services that were accessible to IDUs in the metropolitan Atlanta area between September and December 2009 (GDCPH, 2014). A total of 466 adults ages 19 to 70 years old completed interviews that asked about their HIV status, drug and alcohol use and treatment, injection drug use, and

involvement in intervention programs. Results showed that 87 (19%) injection drug use participants were HIV positive and that of those 87, 43 (49%) reported that they knew of their HIV-positive status. Results also showed that 334 (72%) IDUs had previously accessed drug and alcohol treatment programs. Of the 334 IDUs who had successfully accessed drug and alcohol treatment program, 116 had accessed at least one program within 12 months prior to the interviews. A total of 376 IDUs reported not being able to gain access to drug and alcohol treatment programs in the metropolitan Atlanta area. Of the 466 (100%) participants who completed the interviews, 197 (43%) had accessed syringe and needle exchange programs, and 261 (56%) had received free condoms within 12 months prior to the interview. The GDPH concluded that there were several gaps in HIV screening among IDUs and expressed the need for strategies to increase accessibility to syringe and needle exchange programs in Atlanta.

Seroadaptation refers to the use of HIV status to prevent infection from and transmission of HIV/STDs by adopting specific sexual behaviors (Murphy, Gorbach, Weiss, Hucks-Ortiz, & Shoptaw, 2013). Some common seroadaptive behaviors among MSM include serosorting (e.g., choosing sex partners of the same HIV status); seropositioning (e.g., adopting strategic positioning during sex such that insertive and receptive roles are defined by the partners when having UAI); and using condoms, among other methods (Murphy et al., 2013). Seropositioning is considered a strategic way of minimizing the risk of HIV transmission when having sex with someone whose HIV status is undisclosed.



Murphy et al. (2013) examined seroadaptation from different angles and sought to understand how poor HIV-positive MSM living in Los Angeles adapted to this risk prevention strategy. Murphy et al. used respondent-driven sampling to recruit HIV-positive drug users, MSM, and men who have sex with both men and women (MSMW). Murphy et al. used flyers to recruit members of the target population and gave the participants \$50 each to cover visit expenses. The volunteer participants also were given enrollment vouchers so that they could distribute them to others who met the criteria to join the study. Murphy et al. used respondent-driven sampling from another study (the 2005-2007 National Institute on Drug Abuse [NIDA], 2012) in Los Angeles to recruit 635 HIV-positive poor MSM and drug users.

Results showed that in the last 12 months, 53% of MSM in the Los Angeles area had been homeless. A total of 51% of MSM reported using condoms when having anal sex. MSM who had the same HIV status as their partners accounted for 41% of seroconcordance. Results also showed that HIV negative MSM accounted for 51% of seroadaptation behavior (Murphy et al., 2013). Results from Murphy et al. (2013) showed that seroadaptation was common among poor HIV positive MSM in Los Angeles. Murphy et al. suggested that HIV positive MSM should disclose their status to their sex partners in order for seroadaptation to be an effective and successful risk management strategy. Murphy et al. suggested that MSM consider such HIV/STD prevention methods as proper condom use because seroadaptation also can be a method of HIV transmission.

Stephenson et al. (2011) examined the attitudes of MSM couples in the United States and whether couples-based voluntary counseling and testing (CVCT) was effective

in changing sexual behaviors and reducing the risk of HIV infection. Stephenson et al. recruited 39 MSM study participants from Seattle, Chicago, and Atlanta. The researchers used focus groups to determine whether CVCT could be a possible strategy in reducing HIV transmission among MSM in the three cities.

The criteria for inclusion in Stephenson et al. (2011) study were as follows: The participants must be MSM, be 18 years and older, be current residents in one of the identified cities, and had to have sex partners. The criterion was that an MSM and his partner could participate, but could not be in the same focus group. Black participants accounted for 54% of the participants and 46% were White. Stephenson et al. found that CVCT was an effective way to measure the participants' perceptions about CVCT and sexual behaviors. CVCT provided a forum for serostatus disclosure. Stephenson et al. (2011) found that CVCT was effective in counselling MSM about HIV. Murphy et al. (2013) and Stephenson et al. had consistent conclusions that seroadaptive behaviors were common among HIV-positive MSM in the United States. Stephenson et al. also noted that disclosure of HIV status was an effective method of reducing HIV transmission among MSM. Murphy et al. and Stephenson et al. concluded that seroadaptive behaviors might mitigate the risk of transmission to others.

Likewise, Jin et al. (2007) found that seroadaptation could be an HIV transmission method when having UAI with partners whose viral loads have not been detected. Jin et al., Murphy et al., Stephenson et al. and were consistent in their assertions that seroadaptation can be an HIV risk reduction strategy. However, Jin et al. also contended that disclosing viral load to HIV-infected sexual partners is a negotiating

platform for mitigating HIV transmission. Stephenson et al. further noted that disclosure of HIV status among MSM is not a common practice, a situation that might be a factor in increasing HIV transmission rates.

Vogenthaler et al. (2013) hypothesized that increased involvement in sexual risk behaviors might be influenced by food insecurity. Vogenthaler et al. used a community-based cohort in the San Francisco area to assess a total of 154 sexually active participants. Inclusion criteria included having been sexually active 90 days before joining the study, having UAI and unprotected vaginal sex, and having more than one sexual partner. A repeated-measures design with the same participants was used to assess change over time and to measure how homelessness and food insecurity contributed to risky sexual behaviors among HIV-positive adults in San Francisco. Vogenthaler et al. found that food insecurity had a direct influence on HIV/AIDS vulnerability resulting from the practice of sexual risk behaviors. Vogenthaler et al. concluded that HIV/AIDS treatment programs should incorporate food security interventions to improve the quality of life of HIV-positive persons. Vogenthaler et al. suggested the need for further research to better understand how food insecurity contributes to the increased incidence of HIV and how it affects HIV transmission, treatment, and care.

Stephenson et al. (2011) aimed to understand how poor MSM in the Los Angeles area used seroadaptation as a way of reducing HIV transmission. Stephenson et al. used a secondary multisite database founded by the NIDA (2012) to collect data. Stephenson et al. focused on the factors influencing seroadaptation, namely, sex trade, injection drug use, lack of money, limited resources, demographics, and types and number of sexual

partners. Stephenson et al. found that seroadaptation was prevalent among poor residents of Los Angeles and that young, poor HIV-positive adults exchanged sex to buy food, get money, gain shelter, and buy drugs.

Injection drug use was reported to be the third highest cause of HIV infection and transmission in the United States in a 2007 report by the CDC (2009). Injection drug use is a risk factor for HIV infection and transmission due to syringe and needle sharing with HIV-positive persons can transmit the virus. The CDC sought to identify IDUs in the United States who were HIV positive. The inclusion criteria required the participants to be U.S residents and at least ages 13 years and older. The CDC used the 2004-2007 name-based HIV surveillance system to collect data on 34 U.S. states. Analysis of the data indicated that males who became infected with HIV between 2004 and 2007 accounted for 62.2% of U.S. IDUs. Blacks represented 57.5% of newly diagnosed IDUs with HIV. Results also showed that 74.8% of IDUs were residing in urban areas when they received their HIV diagnosis. The 2004-2006 HIV surveillance system also showed that 40% of the IDUs received their HIV diagnosis late. The CDC (2009) concluded that injection drug use was prevalent among Black people in the U.S. The CDC suggested that HIV prevention interventions such as injection drug use addiction intervention and treatment incorporate community-based outreach programs so that those who are impacted the most can have access to resources such as syringe and needle exchange programs.

Mitchell and Latimer (2009) investigated the perceptions of HIV risk among IDUs who were engaging in unprotected casual sex in Baltimore, Maryland. Measures

used to identify HIV risk factors included identifying differences in HIV prevention strategies between non-IDUs and IDUs in Baltimore, Maryland. Mitchell and Latimer used data from a longitudinal study that had previously investigated HIV risk perceptions and had examined demographics, drug use, and sex risk factors among IDUs. Mitchell and Latimer found that non-IDUs, more so than IDUs, understood HIV susceptibility when engaging in casual sex with no protection.

The conclusions of the CDC (2009) and Mitchell and Latimer (2009) were consistent in suggesting that comprehensive approaches incorporate access to drug abuse treatment and intervention. The CDC also asserted that culturally sensitive HIV-prevention programs should target IDUs and additional HIV-focused condom use intervention programs should be provided to sexual casual partners.

### **Race/Ethnicity and Gender Issues**

Blacks in the United States have been the most impacted by the HIV/AIDS epidemic (CDC, 2014a). In 2010, 84% of new HIV infections among women were the result of heterosexual contact (CDC, 2014a). In 2010, women in the United States represented 20% of new HIV cases (CDC, 2014a). In 2008, 12,000 new infections occurred among women; this number declined to 9,500 new infections in 2010 (CDC, 2014a).

Even though Blacks accounted for 12% of the total U.S. population in 2010, they represented 44% of new cases of HIV that year; in 2011, Blacks represented 41% of HIV cases (CDC, 2014a). A total of 265,812 deaths have been reported among AIDS-

diagnosed Blacks in the United States since 1981. More than 6,630 Black people died of AIDS in the United States in 2011(CDC, 2014a).

Hispanic/Latino Americans also have been disproportionately affected by the HIV epidemic. Hispanic/Latino Americans in the U.S. represented 16% of the population in 2010. However, they also represented 21% of U.S HIV cases in 2010 (CDC, 2014a). In 2011, Hispanic/Latino Americans represented 20% of HIV cases in the United States; in 2011, Hispanic/Latino American males represented 2.9 times the number of new HIV infections than White males (CDC, 2014a). In 2011, female Hispanic/Latina Americans represented 4.2 times the number of new HIV cases than White females in the United States. Approximately 2,310 Hispanic/Latino Americans died of AIDS in 2011, and approximately 99,281 Hispanic/Latino Americans have died of AIDS since 1981 (CDC, 2014a).

Nwankwo (2014) conducted a study to understand the perceptions of African American adults who were HIV-positive and 50 years and older. Nwankwo (2014) focused on their perceptions of their susceptibility to HIV infection prior to diagnosis. Convenience sampling was used to recruit and interview nine African American participants living in the Riverside area (Nwankwo, 2014). Nwankwo found that some of the participants did not believe they were at risk of getting infected with HIV before their diagnosis because they believed that only gay men could contract the virus. Results also showed that eight of the participants had never perceived themselves to be susceptible to HIV infection before they were diagnosed with the virus. Approximately 88.89% of the participants reported having engaged in sexual risk behaviors including not using

protection during sexual intercourse and participating in injection drug use. Nwankwo argued that there should be more patient-doctor conversations about HIV risk and education on sexual behavior. Nwankwo concluded that older African American adults should take responsibility for their sexual behaviors and participate in HIV prevention interventions.

Similar to Nwankwo's (2014) findings, the CDC's (2014a) HIV/STD surveillance data showed higher STD rates among older adults from minority races than among older White Americans adults. The results of Nwankwo's studies were consistent with results reported by the CDC in 2007 (CDC, 2014a) indicating that race and ethnicity are major determinants of health status in the United States.

Reif et al. (2011) investigated why southern U.S. states have had a disproportionately high number of HIV cases and AIDS diagnoses than other states. Reif et al. used CDC surveillance data from 2009 to analyze the high impact of HIV on the U.S. population. They found that the southern states reported the highest rates of new HIV-infection and AIDS diagnoses and that the HIV epidemic has impacted Blacks in the southern states more than other ethnic groups or races.

According to the CDC's (2009) data, Blacks in the southern states had poverty rates that were twice as high as those of Whites. Low SES and high levels of poverty among Blacks living in the southern United States could be considered determining factors in the severity of the impact of HIV on this population. The CDC data also indicated that 64% of Blacks and 48% of White Americans perceived homosexuality as an immoral act. Women in the southern states had the highest HIV incidence rates when

compared to other females in the United States. Heterosexual sex was the biggest cause of new HIV cases among women (84% in 2010). More Black women (87%) and Latina Americans (86%) than White women (76%) became newly infected with HIV through heterosexual transmission (CDC, 2014a).

Other than the Black race, Hispanic/Latino Americans have been impacted significantly by HIV/AIDS in the southern region of the United States. Hispanic/Latino Americans represent approximately 50% of all new HIV diagnoses in the southern states (CDC, 2014a). According to CDC data from 2006 to 2009, Hispanic/Latino Americans living in six of the 10 southern states have had the highest HIV infection rates (CDC, 2014a). More HIV prevention and intervention efforts should focus on the ethnic and racial groups that are the most affected by the epidemic.

### **HIV/AIDS-Related Isolation and Stigma**

Galvan, Davis, Banks, and Bing (2008) conducted a study to gain the perceptions of a sample ( $N = 283$ ) of HIV-positive African Americans about HIV-related support from persons in their close social circles and the association of stigma related to HIV in Los Angeles, California. Galvan et al. collected data from three social service agencies that offered different programs to poor people living in Los Angeles. Galvan et al. used the Berger HIV Stigma Scale to measure the participants' perceptions about HIV-related stigma. Participants also were asked questions about HIV-related alcohol dependence or depression.

Results showed that the participants experienced HIV-related stigma when receiving social resources and support from close friends and family. Galvan et al. (2008)



also found that more than 13% of the participants who were depressed and/or alcohol dependent associated these habits with their HIV status. Galvan et al. concluded that HIV-positive persons who experience the negative effects of HIV-related stigma also have higher levels of depression and more dependence on alcohol. Galvan et al. suggested that future researchers focus on finding various ways to reduce the negative effects of HIV-related stigma among HIV-positive persons who are receiving social recourses and support.

Grov, Golub, Parsons, Brennan, and Karpiak (2010) investigated how loneliness, depression, and health were associated with HIV/AIDS-related stigma among HIV-positive adults ages 50 years and over. The motivation for conducting the study was the lack of evaluation of the additional challenges facing aging HIV-positive adults. To be included in the study, the participants had to be male and female HIV-positive adults ages 50 years and older who were living in New York (Grov et al., 2010). Researchers found that 39.1% of the 914 participants reported depression and that 42% of the depression was directly related to their HIV-positive status and stigma. Grov et al. concluded that HIV-related depression can be directly associated with increased loneliness and HIV-related stigma, among other negative correlating factors caused by aging, such as reduced energy levels.

Emlet (2006) investigated the link between HIV/AIDS-related stigma and aging among HIV-positive adults ages 50 years and older. Emlet used purposive sampling to select participants who shared the same characteristics of aging and life experiences. Emlet used semistructured interview questions to gain an in-depth understanding of the

ways in which HIV/AIDS-related stigma and the challenges of aging affected HIV-positive adults ages 50 years and older. Results showed that 68% of the participants had experienced HIV-related stigma and other negative effects associated with aging. During the data analysis, several themes emerged, including discrimination, stereotyping, rejection, and medical privacy violations (Emlet, 2006). Emlet concluded that most HIV-positive older adults experience the concomitant challenges associated with HIV-related stigma and aging.

Nyamathi et al. (2013) sought to understand AIDS-related stigma by comparing different intervention programs developed to reduce HIV-related stigma. They recruited 68 Indian women ages 18 to 45 years who had been diagnosed with AIDS and examined the different coping mechanisms that they used to reduce AIDS-related stigma. Nyamathi et al. had the women fill out a questionnaire to collect data. Results confirmed that women living with AIDS (WLA) in India experience more internalized AIDS-related stigma than enacted stigma. Nyamathi et al. concluded that because WLA in India face systemic stigmatization, future interventions should focus on decreasing internalized and enacted stigmatization in an effort to improve treatment outcomes.

### **Treatment Compliance**

Beer, Oster, Mattson, and Skarbinski (2014) sought to understand why HIV-infection in the U.S. among Black MSM was disproportionately higher compared to White MSM. Beer et al. used interviews and a survey to collect data that they used to evaluate the factors contributing to HIV transmission among White and Black MSM. Results indicated no significant difference between the sexual risk behaviors of White MSM and

Black MSM. Beer et al. also found that 91% of the 1,004 White MSM in the study, compared to 80% of the 445 Black MSM, adhered to HIV treatment. Factors such as age, SES, and level of education were reported as contributing to HIV treatment compliance. Beer et al. concluded that HIV-infected Black MSM in general might have less success in lowering their viral suppression because of their noncompliance with HIV treatment. Beer et al. suggested that future interventions incorporate the factors contributing to ART noncompliance to reduce disparities among White and Black MSM.

Barclay et al. (2007) conducted a cross-sectional study focusing on understanding the factors, including age, affecting adherence to treatment of HIV-positive adults. Unlike Beer et al. (2014), whose participants were White and Black MSM, Barclay et al. compared medication compliance among younger adults and participants ages 50 years and older. Results showed that out of the 185 HIV-seropositive adults, 68% were younger adults, versus 33% of the older participants who reported being compliant with HIV medication. Barclay et al. concluded that cognitive functions in HIV-positive older adults ages 50 years and older can contribute to their failure to comply with medication protocols.

Beer et al. (2014) concluded that Black MSM did not comply with their HIV treatment while White MSM showed higher compliance levels. Barclay et al. (2007) found that younger adults who were HIV-positive adhered to their medication treatment more than older adults who were HIV-positive. The results of both studies highlighted disparities in HIV medication adherence caused by different underlying factors. Barclay et al. and Beer et al. suggested that education, self-efficacy training, and medication

management for individuals of different ages and ethnicities who are HIV positive should be included in HIV intervention programs.

### **Summary and Conclusions**

The review of the literature identified no studies that have investigated the HIV risk perceptions of adults ages 30 to 49 years in Atlanta, Georgia, prior to their becoming infected with HIV. Peer-reviewed primary research was included in the literature review to ensure high-quality data collection, systematic data analysis, my credibility as the researcher, and a naturalistic setting to gain the trust of the reader (Patton, 2002). A conceptual framework was used in the peer-reviewed primary studies to ensure rigor in this qualitative study. Journal articles and other resources were used to find information about perceptions of HIV risk, transmission, and infection among HIV-positive adults ages 30 to 49 years who were living in Atlanta, Georgia, at the time of the study. It was important to understand the factors contributing to the HIV/AIDS epidemic in Georgia: are MSM, high poverty rates, and injection drug use. Other coexisting factors included the HIV-risk behaviors of different racial/ethnic groups, HIV-related stigma, and disparities in HIV care and treatment. The major themes in the literature review have been concisely summarized in the lens of the HBM.

The HBM was applied as the theoretical frame in relation to health behavior change for this study (Rosenstock, Strecher, & Becker, 1988). The HBM is well aligned with this study because it focuses on an individual's beliefs and attitudes about health. For example, an individual's perception about the benefits and barriers of a recommended action could influence their decision to proceed with that health behavior.

The concepts of the HBM as related to HIV risk perceptions of adults are: (a) perceived risk to HIV infection, (b) perceived risk about the seriousness of contracting HIV infection and its consequences, (c) perceived benefits in reducing HIV risk, (d) perceived barriers or challenges to perform preventive measures, (e) cues to action for a plan or strategy to act on the advised preventive action, and (f) self-efficacy based on the individuals belief that they are able to take action and perform the prescribed action. According to the HBM, an individual's perceptions of their risk of getting infected with a disease and the consequences that come along with that illness influences their decision to take preventive measures. For example, if an individual perceives that they are at risk for HIV infection and believe that benefits of practicing protected sex outweigh the cost of condoms, then that person is more likely to change their health behavior to avoid illness.

The constructs of the HBM align with the major themes in the literature. Nwankwo (2014) conducted a study to understand the perceptions of African American adults who were HIV positive and ages 50 years and older about how they perceived their susceptibility to HIV infection prior to diagnosis. Nwankwo found that eight out of the nine participants had never perceived themselves to be susceptible to HIV infection before they were diagnosed with the virus. The HBM construct of perceived risk was used to analyze the findings of Nwankwo (2014). Other than understanding participants perceptions of risk, the HBM construct of perceived risk was also used to describe the population(s) most affected by HIV (African Americans) and their risk levels. Peterson and Jones (2009) reviewed secondary data to understand the social and structural factors

that contributed to Black MSM being at a high risk for HIV. Peterson and Jones found that Black MSM are the most affected by HIV/AIDS. Peterson and Jones suggested that research and structural interventions focus on HIV prevention among Black MSM. The HBM construct of self-efficacy may be applied to provide training, guidance, and positive reinforcement for Black MSM. Shacham, Lian, Önen, Donovan, and Overton (2013) aimed to understand how low-socioeconomic status (SES) was association with high-risk sexual behaviors, neighborhood characteristics, and HIV interventions. Shacham et al. found that low-socioeconomic status (SES) neighborhoods were more likely to experience HIV clustering. Shacham et al.'s (2013) results were consistent with Hixson et al. (2011) and Rencher (2012) who examined the prevalence of HIV cases in Atlanta, Georgia, in relation to population characteristics. Shacham et al. (2013), Hixson et al. (2011), and Rencher (2012) concluded that the concentration of poverty contributed to the spread of HIV and increased the risk of infection for individuals living in inner-city areas. The HBM construct of perceived barriers can be applied to analyzing how low socioeconomic status (SES) contributes as a barrier to HIV prevention. For example, persons who are financially strained may perceive the cost of condoms as a barrier practicing protected sex. The HBM construct of perceived barriers may influence an individual's decision not to protect them from a perceived illness such as HIV infection (Agha, 2003; Rosenstock, Strecher, & Becker, 1988). Factors such as stigmatization, cost of treatment, social and family acceptance, and peer pressure can influence a persons behavior or choice to take health action (Bandura, 1994). The HBM construct of perceived barriers may be applied to evaluate a person's perception of their psychological

and tangible costs of recommended health action. Furthermore, the HBM construct of perceived barriers can also be used to reduce barriers through the provision of resources such as free condoms, reassurance, and incentives.

The CDC (2014b) defined HIV sex risk behaviors as actions that can increase HIV transmission rates. Examples of sex risk behaviors include having UAI, having multiple sexual partners, not disclosing seropositive status to sex partners who are at risk of HIV infection, and having sex while under the influence of injection drug use (CDC, 2014b; Sullivan et al., 2014). Sexual risk behaviors can increase the risk of HIV infection and transmission as well as other STDs (CDC, 2014b). The HBM construct of perceived severity may be applied to analyze a person's perception about the seriousness of HIV infection and the negative consequences associated with the disease. The HBM construct of perceived benefits could guide the efficacy of HIV prevention and reduce the impact of HIV. The HBM construct of cues to action could guide strategies to prevent further HIV transmission by providing the how-to information, promoting awareness, and developing reminders.

Chapter 3 provides a detailed discussion of the research methodology, sampling recruitment and selection, instrumentation, data collection and analysis methods, threats to validity, and the pilot study.

## Chapter 3: Research Method

### **Introduction**

The purpose of this phenomenological study was to understand the lived experiences of HIV-infected adults ages 30 to 49 years in Atlanta, Georgia, by gaining their perceptions of risk prior to contracting HIV. The literature review identified studies related to prevailing perceptions about HIV/AIDS; however, the HIV risk perceptions of the target population specifically in relation to MSM, poverty, and injection drug use prior to developing HIV had not been investigated. Furthermore, no phenomenological studies had been conducted with this same target population. I followed a phenomenological approach to understand the participants' perceptions and interpretation of the meaning of their experiences relevant to the phenomenon (Creswell, 2013). This study could be significant to the field of public health in providing a better understanding of the subject matter.

Chapter 3 provides a detailed description of the research design and concept of the rationale for the research tradition; an explanation of my role as the researcher; and the logic of the study methodology, including the sampling selection, recruitment, and data collection and analysis; a description of the pilot study and its purpose; and explanations of the instrumentation constructs, threats to validity, ethical procedures, and issues of trustworthiness that could have affected the study.

### **Research Design and Rationale**

Atlanta, Georgia ranked number one among all cities for new HIV/AIDS cases in 2013 (CDC, 2015a). In Atlanta, the continued high rates of HIV and HIV/AIDS



infections are a major concern among stakeholders such as public health professionals. Data from the GDPH( 2014) indicated that Georgia ranked fourth in 2011 with new HIV diagnoses. In 2012, Georgia had 50,436 HIV-infected persons; in 2005, it had 33,025 HIV-infected persons (GDPH, 2014). HIV in Georgia is concentrated in four counties that fall within an area of approximately 187 square miles of downtown Atlanta (Sullivan et al., 2014). In 2010, there were more than 1,951 HIV-positive people per 100,000 population in metropolitan Atlanta (Sullivan et al., 2014). In order to understand why Atlanta continued to increase in numbers of HIV cases at an alarming rate, I conducted this study to understand the HIV risk perceptions among HIV-infected adults ages 30 to 49 years in Atlanta, Georgia. The main research question aimed to understand the lived experiences of HIV infected adults 30-49 years old with respect to their perceptions of risk prior to developing HIV infection.

According to Reif et al. (2011), the southern states have been disproportionately impacted by HIV. The southern U.S. states account for 37% of the U.S. population; however, they reported 49% of HIV diagnoses in 2011 (CDC, 2014b). In 2009, there were a total of 17,774 (48%) deaths related to AIDS in the southern United States (CDC, 2014b). The northeastern part of the country reported the second highest percentage (24%) of AIDS-related deaths, the western states were third at 17%, and Midwestern states ranked last with 11% (CDC, 2014b). Reif et al. noted that Georgia was among the southern states impacted the most profoundly by the HIV epidemic; they identified other southern states impacted by HIV as Florida, South Carolina, North Carolina, Alabama, Tennessee, Texas, and Louisiana.

All southern states have been characterized by researchers as having similar sociodemographic and disease conditions that have contributed to the high incidence and mortality rates of HIV. The main contributors to the higher annual rates of HIV infection in Atlanta have been MSM, injection drug use, and high levels of poverty (Sullivan et al., 2014).

I followed a qualitative methodology to examine and more fully understand the complex nature and coexistence of poverty, injection drug use, and MSM in relation to the high prevalence of HIV in Atlanta. I selected a phenomenological approach to give the participants the opportunity to provide complex textual descriptions of their perceptions of HIV risk prior to being infected and their lived experiences after contracting the infection. A qualitative approach was used to gather information about the participants' individual experiences and life situations: their sexual behaviors, beliefs, opinions, and emotions; and their relationships with their partners, family members, and health care providers. According to Creswell (2013), phenomenological methods have been used by researchers to understand perceptions of life events and situations.

I used a phenomenological design to obtain the perceptions of HIV-positive adults who had experienced the phenomenon under investigation, conduct in-depth interviews, describe the participants' perceptions of their life experiences, and identify emerging themes. According to Manen (1990), "Phenomenological reflection is retrospect, not introspective, and it is a reflection of what a person has experienced or lived through" (pp. 9-10). Manen asserted that phenomenological research not only focuses on the lived experiences of the participants but also describes how the individuals experienced the

phenomenon. A phenomenological approach provides depth and richness because the underlying meaning of the individuals' lived experiences is revealed (Creswell, 2009).

### **Role of the Researcher**

I conducted this qualitative study by being the interviewer, data collector, and data analyst. Qualitative researchers must conduct thorough reviews of the literature by examining relevant documentation and serving as the key data collection instrument (Creswell, 2009). I approached the problem being investigated with an open mind and without preconceived perceptions because I wanted to focus on understanding the perceptions of the participants. According to Kothari (2005), qualitative researchers must determine the most appropriate sample sizes based upon the purpose and criteria derived from the objectives of the studies. I developed the RQ and scheduled the interviews (Kothari, 2005). I followed a step-by-step procedure during the interviews to minimize researcher bias (Kothari, 2005). I maintained the participants' privacy and followed the ethical guidelines of the Institutional Review Board (IRB) of Walden University (approval #08-31-15-0242901) related to the recruitment of the participants, the interviews, and the storage of data (Kothari, 2005).

### **Methodology**

#### **Target Population**

According to Creswell (2005), target populations comprise individuals who possess common characteristics that allow them to fit the criteria established by the researchers. The population for this study were HIV-positive adults ages 30 to 49 years who were living in the metropolitan Atlanta area at the time of the study. In 2012, this

cohort had the highest numbers of new HIV infections (GDPH, 2014). The metropolitan Atlanta area was chosen because more than 60% of the HIV cases in Georgia are clustered in four counties (Fulton, DeKalb, Clayton, and Gwinnett) that fall within 187 square miles of downtown Atlanta. The rate of HIV in the cluster is 1.34% (Rosenberg et al., 2014). Members of this target population were chosen because they experienced the phenomenon and fit the study criteria (Kvale, 1996).

### **Sampling**

I used purposive sampling as the most appropriate way to obtain the participants for the study. Purposive sampling in this qualitative study included the identification and selection of individuals who were knowledgeable about HIV perceptions and were HIV positive. Purposeful sampling depends on information-rich individuals who are knowledgeable enough to speak to the central issue of the study (Burmeister & Aitken, 2012; Sandelowski, 2001). According to Patton (2002), the sample should meet the study criteria; they also should be able to provide the information needed for the study (Maxwell, 1997).

Twelve HIV-positive persons ages 30 to 49 years who lived in the metropolitan Atlanta area and responded to the recruitment flyers participated in this study and provided unique experiences and contextual perceptions (Creswell, 2013). This sample was considered sufficient because it represented HIV-infected persons who were assumed to have knowledge related to the RQ. I interviewed the participants to obtain my data.

## **Research Instruments**

I was the main research instrument for this study. I collected the data by conducting interviews with the participants, all of whom had met the inclusion criteria and had signed the consent form. According to Harwood and Garry (2003) and Weber (1990), researchers need to verify similarities and differences in all categories to ensure that the data are being represented accurately.

As explained by Guthrie, Yongvanich, and Ricceri (2004) and Sandelowski (2001), collecting and analyzing data concurrently allows researchers to recognize the point of saturation by identifying when no new or relevant information is emerging and no more data need be collected. After transcribing the interview responses, I analyzed the collected data by coding and categorizing them using NVivo v.10. Data analysis entails verifying the reliability and validity of the findings by closely examining the data (Kothari, 2005). After completing the data analysis, I made recommendations regarding the theory guiding this study, public health practice, and future research based upon what the study revealed through the data collection, data analysis, and discussion.

The relationship between saturation and sample size was important in this study. According to Guthrie et al. (2004) as well as Sandelowski (2001), data saturation in a qualitative study indicates an optimal sample size. Saturated data ensure comprehension and completeness due to replication (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Lack of data saturation can negatively affect the data analysis process (Cavanagh, 1997). Data collection and analysis occur concurrently such as in an iterative cycle to determine data saturation (Creswell, 2009). I wrote memos during the data analysis. Audiotaping

the interviews also captured important information about the respondents' HIV risk perceptions, attitudes, demographics, beliefs, and sexual risk behaviors.

I asked open-ended questions during the individual and private interview sessions to allow the participants to share details about their HIV risk perceptions and personal lived experiences with HIV. Each interview began with a general question: "Based on your experiences, can you describe for me how you felt the first time you found out that you were infected with HIV?" Prompts were asked to follow up with the initial responses. The participants were free to answer them without any influence or pressure from me (Creswell, 2009). All of the interviews lasted approximately 15 to 40 minutes. According to Garg (2006), researchers must consider that the depth of responses might affect interview schedules.

### **Pilot Study**

Before conducting the initial study, I conducted a pilot study with three volunteers. Pilot studies allow researchers to assess the validity and reliability of their interview questions. The three pilot study participants did not participate in the main study. The pilot study helped me to address any issues relevant to the interview protocol. According to the findings from the pilot study, there were no modifications needed for the interview or data collection protocols (Sampson, 2004).

### **Recruitment of Participants**

Participants were recruited from the Infectious Disease Group of Atlanta (ID Group of Atlanta), a clinic that is a medical practice offering health care and HIV/AIDS services (see Appendix B). After potential participants who met the inclusion criteria

expressed an interest in joining the study, I contacted them to explain the consent form, have them sign it, and schedule dates and times for the interviews. The letter of consent was written in plain language to describe the purpose of the study and the nature of their involvement, including their rights and benefits, as well as any risks, that might be associated with participation. Participants were informed through the letter of consent that they voluntarily chose to participate in the study. The letter of consent also informed participants of the right to withdraw from the study whenever they chose to. Participants were also informed that there were no negative consequences or penalty if they chose to withdraw from the study. Each individual participant signed and dated the consent form, opening the way to conduct the interviews. The participants had to have received a diagnosis of HIV at least 12 months before they participated in the study.

### **Data Collection**

The process of collecting data involved a phenomenological approach that allowed the participants to describe their lived experiences in depth (Creswell, 2009). These descriptions can include emotions, memories, reactions, thoughts, and feelings (Patton, 2002). The participants also are able to describe the natural environment or setting where their lived experience occurred (Patton, 2002). Open ended questions were used in the unstructured interviews to understand the participants' HIV risk perceptions prior to being diagnosed with the virus. I conducted one-on-one interviews with 12 participants. Participants were informed that they were free to choose an interview site that was convenient and private for them. All participants chose to be interviewed at the ID Group of Atlanta.

Each interview lasted approximately 15 minutes to 40 minutes. I captured information about the participants' demographics, sexual behaviors, and perceptions/attitudes toward HIV/AIDS. The open-ended questions allowed the participants to share their lived experiences and perceptions of HIV risk prior to infection without implied answers (Creswell, 2009). I audiorecorded the interview responses for the purposes of transcription and analysis. All participants received a \$20.00 gift card as a gesture of thanks.

### **Debriefing Procedures**

Qualitative researchers select participants who will provide rich information that will answer their RQs and provide a better understanding of the phenomena under investigation (Creswell, 2009). The debriefing procedure ensures that study participants receive truthful and accurate information without withholding the nature or purpose of the study (Creswell & Miller, 2000). The debriefing procedure in this study included a description of the purpose and nature of the study, and how data was collected. The debriefing procedure also described the process of answering the participants' questions, ensuring that they understood the research procedure, explaining the role of deception in research, asking the participants for suggestions to improve the study, thanking them for participating, providing contact information in case they had future questions or concerns, and sharing the results with interested participants (Creswell & Miller, 2000).

### **Follow-Up Procedures**

During the interview sessions, I informed all participants that follow-up interviews might have to be scheduled in case more detail and/or elaboration about their



responses was needed. After the interviews were completed, I determined that all information provided was adequate and that no follow-up interviews were needed.

### **Data Analysis and Plan**

The data collection and analysis occurred simultaneously in this study. Skillful interviewing and appropriate coding techniques ensured an accurate analysis of the data. According to Patton (2002), coding is a repetitive process that requires qualitative researchers to link the data to the RQ. Qualitative codes must capture the main elements of the data to develop patterns and categories based upon the analysis. Once the codes were established, I assigned names and definitions to the categories (Creswell, 2009).

I used memoing throughout the data analysis, and I recorded reflective notes detailing observations from the data. I wrote memos noting ideas and insights and included the memos as additional data to be analyzed. The coding process was guided by Creswell's (2009) process, whereby the first step required an exploration of the database to obtain a general sense of the data. The recorded data were transcribed, organized, reviewed using the HBM as the theoretical basis. Subthemes were created from coded data and major themes were developed.

After formulating the themes, I used computerized programs for data entry and storage. I entered my notes from observations, interviews, and memos into NVivo v.10, which I used to organize and extract relevant data and to define units and pieces of meaning from interview responses to form central themes (QSR International, 2007). I used narrative descriptions and tables to display the themes, thematic categories, and

codes. To identify emerging themes, I developed a textual comparison based upon the assigned identification number for each participant and the interview questions.

According to Patton (2002), qualitative researchers should develop coding schemes before analyzing their data. Coding schemes require the organization and classification of data in ways that make sense. Coding schemes also lead to the discovery of primary patterns (Patton, 2002). Focusing on primary patterns and themes helps to minimize recall biases and other challenges during data analysis and coding (Patton, 2002). According to Miles, Huberman, and Saldana (2014), the use of computer software to analyze the data saves time when dealing with a large data set and also improves the validity and auditability of the data.

### **Issues of Trustworthiness**

#### **Internal and External Validity**

Transferability refers to how much findings can be inferred or generalized from the original study to other settings, contexts, or groups (Sandelowski, 2001). Validity aims to measure the truthfulness of a study (Trochim, 2006) and assess the accuracy and credibility of the data. Researcher bias, inflexible knowledge related to the theoretical framework, and subjectivity are major threats to internal validity (Creswell, 2005). According to Creswell (2005), inflexible knowledge refers to the inability to apply existing knowledge to new situations. Flexibility refers to the ability to access knowledge from the original learning and apply it in new contexts. Trochim (2006) noted that the validity of qualitative studies can be found in solid conclusions. I used member checking immediately after completing the interviews to allow the participants to verify the

accuracy of my interpretations of the meanings of their responses (Janesick, 2011).

Creswell (2007) asserted that member checking allows participants to confirm the information provided during the interviews, verify the accuracy of the collected data, and add credibility to the study.

According to Creswell and Miller (2000), internal and external validity include the criteria or standards used to judge the quality of qualitative research. To ensure the trustworthiness of this study and reduce bias, my personal views, feelings, or thoughts were set aside while I was collecting and interpreting the data. External validity involves generalizing the findings to other conditions, settings, or populations (Trochim, 2006). The findings were not generalized to other populations outside of the state of Georgia because purposive sampling was used to get a small sample who fitted the HIV demography of the metropolitan Atlanta area, which is characterized by clusters.

### **Conformability**

I used conformability to verify that my interpretation of the data was accurate and representative of the information that the participants provided. Janesick (2011) asserted that the findings of any study must be an accurate assessment of the participants' information and that researchers' views or perceptions should not be included in the findings. I included selected quotations from the transcribed text in this study to provide the reader with verbatim accounts according to the participants' own words.

### **Ethical Procedures**

I ensured that the participants voluntarily joined the study, I provided them with and explained the informed consent, and I assured them that their privacy would be

maintained (Creswell, 2013). The ethical procedures for this study were guided by Walden University's IRB.

### **Ethical Concerns Related to Recruitment**

I used the IRB approval documentation to negotiate access to the recruitment site. The participants were HIV-infected adults ages 30 to 49 years who were living in Atlanta at the time of the study. The participants were recruited from the ID Group of Atlanta, an HIV/AIDS clinic that provides care and services to patients with HIV/AIDS. I provide the clinic manager with the IRB documentation ensuring that the rights and welfare of potential participants would be protected, and clinical staff helped to identify appropriate locations for the recruitment flyer, which provided important information about the study. Clinical staff also helped to distribute flyers to patients. All potential candidates at the clinic were provided with a consent form. Signing the consent form meant that the participant had been informed about the study and had volunteered to be in the study.

### **Ethical Concerns Related to Data Collection/Interventions**

Informed consent ensures transparency and respect for the study participant through an open and honest communication process initiated by the researcher. As the researcher, I wrote the informed consent in a manner that ensured it was readable and easy for the participant to comprehend. I explained the nature of the study to the individuals who responded to the recruitment flyer and stated they wanted to be part of the study. Participants made their own informed decisions whether or not to join and participate in the study. No participant was coerced into participating, and all participants

were advised that they had the right to withdraw at any time without any negative consequences. No clinical trials were carried out on the participants.

### **Treatment of Data**

All participants who met the inclusion criteria had to read and sign the consent form before being interviewed. To ensure the participants' privacy, I used numbers to identify the 12 participants (Creswell, 2013). No identifiable information such as age, gender, or date of birth of the participants was used in the findings. All interviews were audiotaped, and notes were taken during the interviews. I stored all recordings, research files, interview transcriptions, and any other documentation pertinent to the study in a password-protected computer and locked home office cabinets. As per university requirements, they will be stored for 5 years and then destroyed.

### **Summary**

In Chapter 3, I described the methodology in sufficient depth so that other researchers, should they so choose, can replicate the study. Included in Chapter 4 are the findings derived from the data analysis.

## Chapter 4: Results

### **Introduction**

The purpose of this phenomenological study was to understand the lived experiences of HIV-infected adults ages 30 to 49 years in Atlanta, Georgia, by gaining their perceptions of risk prior to contracting HIV. The theory that guided this study was the HBM. The literature review identified a gap in knowledge in respect to the factors affecting the HIV/AIDS epidemic in Atlanta, Georgia. The literature review indicated that adults ages 30 to 49 years had the highest HIV incidence in Georgia. As of January 2016, no researchers had conducted studies seeking understanding of the lived experiences of HIV-infected adults ages 30 to 49 years in Atlanta with respect to their perceptions of risk prior to contracting HIV. The study was guided by one RQ: What are the lived experiences of HIV-infected adults ages 30 to 49 years with respect to their perceptions of risk prior to developing HIV infection? In Chapter 4, I describe the pilot study and setting; present demographic information about the participants; and provide an overview of the data collection and analysis, evidence of trustworthiness, and findings. I conclude with a summary.

### **Pilot Study**

The pilot study was conducted before the main study. The pilot study was conducted to evaluate the interview protocol. The ID Group of Atlanta was used as a recruitment and interview site for the pilot study and later for the main study. Three eligible participants who were separate from the 12 participants in the main study and who had been HIV positive for at least 12 months, were between the ages of 30 and 49

years, and were residing in Atlanta at the time of the study were interviewed for the pilot study before the main study was conducted. Based upon the feedback from the pilot study, the original format of the data collection process for the main study did not need revisions.

### **Research Setting**

Prior to obtaining IRB approval, I obtained a letter of cooperation from the community partner, ID Group of Atlanta. Upon receiving IRB approval, I immediately established rapport with the clinic's management front office and clinic staff by thanking them for volunteering to help to distribute the recruitment flyers in different areas of the clinic so that patients could pick them up in privacy. Twelve participants who responded to the recruitment flyers and who met the inclusion criteria were provided with information about the verbal and written informed consent procedures before being interviewed in a private room at the ID Group of Atlanta. Upon meeting the participants, I thanked them for their voluntary interest and willingness to participate in the study. I also thanked the participants for their time and proceeded to explain the general study procedures. I provided a clear description of the RQ and purpose of the study, and I assured the participants that their privacy and confidentiality of their responses would be maintained.

All interviews were conducted individually, privately, and in person. Interviews were recorded after participants voluntarily agreed to be interviewed and audiotaped using a digital recorder. The shortest interview lasted approximately 15 minutes; the longest interview was about 40 minutes. If I needed clarification of any responses, I

asked for it during the interview session. No participants expressed any personal or organizational conditions at the time of the study that might have influenced my interpretation of the responses.

### **Demographics**

Table 1 illustrates the demographic factors representing all 12 study participants. Ten (83%) participants were men, and two (17%) were transgender. Eleven of the 12 participants were Black (92%), and one was White (8%). Three participants had completed graduate school; two had completed undergraduate college; one had three years of college education; five had completed high school; one had a GED. Eleven participants (92%) were sexually active at the time of the interview. The one participant who was not sexually active was transgender. All 12 participants were living in Atlanta and had been diagnosed with HIV for at least 12 months. Participant ages ranged from 33 years to 48 years ( $M = 40$  years). Table 2 provides information relevant to HIV (i.e., mode of infection, gender of participant and partner, year of diagnosis, and number of years living with HIV).



Table 1

*Demographic Characteristics of Participants*

Participant	Age	Gender	Race	Level of education	Sexual status
1	36	Male	Black	Master's	Active
2	38	Male	Black	Undergraduate	Active
3	45	Male	Black	GED	Active
4	35	Transgender	Black	High school	Active
5	47	Transgender	Black	High school	Not active
6	46	Male	Black	3 years of college	Active
7	35	Male	Black	High school	Active
8	35	Male	Black	High school	Active
9	33	Male	Black	Undergraduate	Active
10	48	Male	Black	High school	Active
11	34	Male	Black	Master's	Active
12	48	Male	White	Master's	Active

Table 2

*Mode of Infection, Gender of Participant and Transmitting Partner, Year of Diagnosis, and Years Living With HIV*

Participant	Mode of HIV Infection	Gender of participant at time of study	Gender of participant at time of transmission	Gender of transmitting Partner	Year of HIV diagnosis	Years living with HIV
1	Unprotected sex	Male	Male	Male	2014	1
2	Unprotected sex	Male	Male	Male	2002	13
3	Unprotected sex	Male	Male	Female	2004	11
4	Unprotected sex	Transgender	Male	Male	2006	9
5	Rape	Transgender	Male	Male	1991	24
6	Unprotected sex	Male	Male	Male	1994	20
7	Unprotected sex	Male	Male	Female	2002	13
8	Unprotected sex	Male	Male	Male	2008	7
9	Unprotected sex	Male	Male	Male	2008	7
10	Unprotected sex	Male	Male	Unknown	1997	18
11	Unprotected sex	Male	Male	Male	2011	14
12	Unknown	Male	Male	Male	1994	21

**Data Collection**

Prior to each interview, I collected demographic data from each participant on age, race, gender, highest level of education, year diagnosed with HIV, and number of

years living with HIV. One RQ served as the central guide for this qualitative study: What are the lived experiences of HIV-infected adults ages 30 to 49 years with respect to their perceptions of risk prior to developing HIV infection? I used a 15-item questionnaire to guide the interview sessions, address the RQ, and obtain deeper insight of the participants lived experiences with HIV. As mentioned previously, I audiorecorded the interviews, which lasted between 15 and 40 minutes. The length of each interview was determined by the amount of detail and description that each participant shared. I used memoing to recall nonverbal communication, such as participants' emotions and facial expressions. I used member checking after each interview to ensure that my observations and interpretations were accurate.

### **Data Analysis**

The data analysis included memoing, transcribing the field notes and interview responses, organizing and evaluating the collected data, creating codes, conceptualizing, formulating subthemes, examining relationships and displaying data, categorizing the data, formulating major themes, checking the validity of codes, identifying patterns and themes using codes, and interpreting the data using NVivo v.10. The software helped me to organize my notes; mark the text; organize the codes; retrieve text in various grouping schemes; and manage, shape, and make sense of the data.

After collecting the data, I transcribed all documented field notes and recordings to develop coding concepts and notes. I used code notes to describe the meaning of different terms through everyday language instead of technical jargon, which made it easier to identify the code labels and explain their meanings (Babbie, 2013). Theoretical

codes were created based on the HBM to help me to understand the relationships among the concepts and provide deeper meanings of them (Babbie, 2013). The compilation of these memos helped me to describe and define the concepts (Babbie, 2013).

I used textual analysis to analyze the content and meaning of my notes. I entered written text such as notes and quotes under categories in NVivo v.10 and marked each unit of analysis with a code. The coding of the transcribed data included highlighting statements from the participants relevant to the RQ. Statements that were not relevant to the RQ were not coded. I used data reduction by sorting, removing, and organizing data to make conclusions that could be verified.

Data reduction helped me to makes sense of the data and organize the axial codes. For example, Participant 9, a 33-year-old man who had been diagnosed at age 26, was responding to the following interview item: Based on your experience, describe how much your doctors and/or other health care providers like nurses talked to you about sex education and HIV prevention before you developed the infection. The respondent's statement that he was not happy that he found out about his HIV diagnosis when he got a medical discharge from the military was related to the interview item. However, one of his statements was not directly related to the interview item because it referred to how much one of his former military colleagues got paid after he sued for medical discharge. Participant 9 stated, "He had basic training, and they had to send him back. They tell him, 'You had this,' and sent him back. He talking like, 'Well, that messed me up'...He's getting almost full pay...80%. He's getting paid for it."

Selected transcriptions imported into NVivo v.10 summarized the themes supported by the quotations or statements used to code the data. The responses helped me to identify core themes and patterns. I used open coding to segment the interview items and their relationships to the participants' responses.

When analyzing qualitative data, researchers should focus on using the data to describe the phenomena and the meaning from the perspectives of the participants (Janesick, 2011). Janesick (2011) explained that researchers must identify repetitive statements, themes, meaning units, and categories to understand the participants' perspectives. The goal of my data analysis was to understand what it meant to the participants to live with HIV. Textural-structural descriptions were developed from the themes that were generated from the analysis of the responses to the 15 interview items. A log of interview items, narrative descriptions, emerging themes, subthemes and codes were used to present results of the phenomena being studied.

I used NVivo's data organization option to code and form subcategories of codes developed from the core themes. Located in the Results section are the results and themes developed from the subthemes and the participants' responses. One discordant case in the data analysis was Participant 5, who was not sexually active at the time of the study. The other discrepancy involved Participant 12, a 48-year-old man who had been diagnosed at age 27, who stated that the only way to reduce HIV infection was by making HIV preventive medicine such as PrEP (pre-exposure prophylaxis) available to the public.

### **Evidence of Trustworthiness**

Four criteria were used to ensure trustworthiness for this study. Credibility, transferability, dependability, and confirmability were the qualitative criteria used to assess the trustworthiness of naturalistic inquiries to guide this phenomenological qualitative study (Guba, 1981). To address credibility, I ensured that a true picture of the phenomenon being studied was presented. I developed an early rapport with the staff at the ID Group of Atlanta by meeting with the managing physician and his staff. I introduced myself as a Walden doctoral student in public health. Credibility can be achieved by consulting the appropriate documents and making preliminary visits to the participating organizations before data collection begins (Shenton, 2004). During the consent process, participants were informed that they had the right to not answer all questions, stop the interview, or completely withdraw during the interview process without penalty. According to Guba, researchers must provide participants with information about their unconditional right to withdraw from studies while seeking approval for participation. Before obtaining IRB approval from Walden University, I gained permission to use the established interview items from another author. According to Shenton (2004), it is important for qualitative researchers to incorporate “correct operational measures for the concepts being studied” (p. 64). For example, researchers can use specific procedures such as the questions used to collect the data and the methods of data analysis from those that have been used successfully in previous comparable projects (Shenton, 2004).

I used triangulation to verify information across interview respondents. According to Shenton (2004), “Individual viewpoints and experiences can be verified against others in the interview session” (p. 66). One participant mentioned that he had witnessed “HIV stick parties” when he lived in New York. Another participant mentioned that one of his lived experiences with HIV was encountering “bug chasers” in Atlanta. I asked the later respondent whether bug chasers were the same as HIV stick parties to check whether the information referred to similar circumstances. Shenton believed that qualitative researchers should exploit opportunities “to check out bits of information across informants” (p. 66) by comparing descriptions from one participant with those of others in comparable positions. I also used member checking to verify the accuracy of the data during and immediately after the interview sessions. According to Lincoln and Guba (1985), member checking might occur during or following interviews.

The findings and conclusions of this qualitative study are not transferable to other populations. I used purposive sampling to obtain a sample of 12 HIV-infected adults who were living in the metropolitan Atlanta area at the time of the study. Because the findings are specific to a target population in a particular geographical area, the results cannot be generalized to other locations, contexts, or settings.

To address dependability, I provided a detailed description of the study for use by future researchers. According to Creswell (2007), thick descriptions of evidence-based research practices validate the results of the interviews. To ensure confirmability, I reported the lived experiences of the participants, who were adults living with HIV, according to their descriptions, not my preferences or biases. To enhance confirmability,

I confirmed the results by checking and rechecking the data obtained from interview recordings and transcriptions. I used triangulation to reduce the effect of the researcher's bias when reporting findings.

## **Results**

This section addresses the responses to each interview item as gleaned from the data analysis. The findings are reported with each interview item to facilitate a deeper understanding of the lived experiences of HIV infected adults and their perceptions of HIV risk. Collected data identified ten themes. The tables provide an overview of all of the themes that emerged. Quotations from the interview responses supported the subthemes. I used tables to provide examples of the participants' responses to the interview items. The modified version of van Kaam's system of qualitative data analysis include identifying theme categories, grouping the data, identifying patterns, reducing the textual data, clustering, identifying themes, and eliminating (Moustakas, 1994). The following quotations provide a brief narrative description of what each participant shared during the interview process.

### **Interview Item 1**

Based on your experience, can you describe for me how you felt when you first knew that you have been infected with HIV? Responses to Interview Item 1 revealed the initial feelings and reactions of the participants upon learning that they were HIV positive. Most participants felt that they had received a death sentence; some expressed shock, disappointment, disbelief, betrayal, revenge, devastation, hurt, sadness,

depression, and so on. Two participants (1 & 9) felt disappointed. Participant 1, a 36-year-old man who had been diagnosed at age 35, stated:

But I guess being in public health, the disappointment was you're always on the other side of the table, and then it kinda flipped on me and I was on the other side of the research, you know, on the other side of the counseling, on the other side of the doctor's visits and all of that stuff.

Four participants (3, 8, 9, & 12) felt that their HIV diagnosis was a death sentence. Participant 8, a 35-year-old man who had been diagnosed at age 28, commented:

I kinda felt like that was the end of the world. Like, it was like, okay, might as well I just die right now because it was very devastating and that's just based on the stigma, in terms of like what you hear growing up. Saying that it's more of a death sentence than anything else. I didn't have strength and power I would be like, do something stupid, because at that point it was very hard.

Analysis of the responses showed that the majority of participants experienced negative feelings and reactions after being diagnosed as HIV positive. Only Participant 5 dealt with her diagnosis well. Overall, results revealed strong emotional responses from the participants. The HBM was used to interpret participants self reported reactions of HIV as a negative health consequence. The HBM construct of perceived severity was applied in the results in context to the participant's feelings on the seriousness of contracting HIV. For example, one of the self reported negative health consequence was participant's expression that their HIV diagnosis was a death sentence. The HBM will be



discussed in detail in chapter 5. The HBM is the theoretical base for preventive HIV measures and as an effective framework for health behavior change in HIV intervention strategies in relation to Interview Item 1. Table 3 presents some of the responses to Interview Item 1.

Table 3

*Initial Feelings and Reactions of Participants Upon Learning That They Were HIV Positive*

Responses & themes	No. of participants	% of participants
Disappointed	2	17%
Death sentence	4	33%
Shocked	4	33%
Did not believe HIV Diagnosis	1	8%
Devastated	3	25%
Depressed	3	25%
Revenge	1	8%
Emotional	5	42%
Betrayed	1	8%
God gave up on him	1	8%
Took it very well	1	8%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

### **Interview Item 2**

Based on your experience, describe what you knew about your risk of getting HIV. Responses to Interview Item 2 revealed what the participants knew about their risk of becoming infected with HIV. The participants noted that their knowledge about HIV risk was gained from different sources, including television; family members, friends; neighborhoods; internet sources; social settings; campaigns; rumors; and personal experience, such as the deaths of friends and family members who had been infected with HIV. Eight participants said they knew about the risk of getting HIV. Participant 5, a 47-year-old transgender who had been diagnosed at age 23, stated:

Before I even knew about HIV, the risk that I knew was transmitting blood-to-blood, sharing needles, and homosexuality. They tried to make that the biggest hit because oh, you're gay you're gonna get it, I'm like no, somebody needs to educate you. I say that's why so many heterosexuals have it because they feel like they can't get it. You know what I'm saying? And like I tell them all the time, while this girl doesn't know her boyfriend sleeping with a tranny and the tranny probably got it or the boy probably got it and he bring it back home to her. Now she got it. Now it's a three-way thing, and they'll never realize it. That's how it's done.

The participants demonstrated ample knowledge of their risk of HIV infection prior to diagnosis. The HBM construct of perceived risk was used as a lens to interpret the results related to Interview Item 2. For example, participant's expressed their perception of the risk of acquiring HIV. This construct will be discussed in detail in chapter 5. Table 4 presents some responses to Interview Item 2.

Table 4

*Participants' Knowledge About the Risk of Becoming Infected With HIV*

Responses & themes	No. of participants	% of participants
Knew about the risk of HIV	8	67%
HIV is a gay disease	1	8%
HIV is a Caucasian disease	1	8%
Unprotected sex	2	17%
Trusting the wrong people	1	8%
Never knew about HIV risk	1	8%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

**Interview Item 3**

Based on your experience, describe to what extent, if any, did you believe you could be personally be at risk to HIV infection prior to developing the virus. Responses to Interview Item 3 demonstrated the extent to which the participants perceived themselves as personally at risk of HIV infection. Perceived risk referred to the degree at which participants believed that they could get HIV infection. Understanding the extent to which the participants perceived that they were at risk of getting infected with HIV was important because it measured their likelihood of developing the illness. Six participants (1, 2, 5, 6, 8, & 12) believed that they were personally at risk of HIV infection.

Participant 1 stated:

Personally, I knew I was at risk with having unprotected sex. However, sometimes being human and depending on the situation, we get willing to take risks. And a lot times we think about it after the fact, why did I do that? But upfront, you know you're thinking I'm just having fun, I'm gonna do me. You know I'm happy, I know this person that I'm with, I trust them, and I know that they trust me but, it's the after that just really kinda gets to you. But like I said I knew I was at risk, because of my actions.

Six participants (3, 4, 7, 9, 10, & 11) did not believe they were personally at risk of getting HIV infection. Participant 11, a 34-year-old man who had been diagnosed at age 20, stated, "Like zero percent. It just didn't include me. That's what I thought."

Participants expressed a wide variation of whether and the extent at which they perceived that they were at risk of getting infected with HIV. The HBM construct of

perceived risk was used to describe the extent to which participants individually believed that they were at risk of getting infected with HIV. The extent to which the participants believed about their personal risk of getting infected with HIV could have influenced how they processed health information and how motivated they were to engage in particular risky behaviors. The concept of how perception of HIV risk could help to understand high-risk sexual behavior is discussed in more detail in Chapter 5. Table 5 presents some responses to Interview Item 3.

Table 5

*Extent to Which Participants Perceived Themselves as Personally at Risk of HIV*

Responses & themes	No. of participants	% of participants
Knew I was at risk of HIV	6	50
Did not think I was at risk of HIV	6	50

*Note.*  $N = 12$

#### **Interview Item 4**

Based on your experience, can you help me to understand how often you used condoms before you became infected with HIV? For Interview Item 4, the participants shared information about how often they used condoms before becoming infected with HIV. One of the main barriers mentioned for not using condoms was their expense. Other reasons included that female partners were already using contraception and did not need condoms because the risk of getting pregnant had been reduced; condoms reduced the sensation during sex; they were in concurrent or monogamous relationships, so they assumed there was no need for protected sex; they trusted their sex partners; they were drinking heavily; and sexual encounters were spur of the moment. Eleven participants did not always use condoms before becoming infected with HIV. Participant 11, for example,

said, “I would say 50-50. Sometimes I took risk when I shouldn’t have sometimes, and other times, I went ahead and used protection. As of now, I use protection all the time, to keep from getting anything else, too.”

Despite their knowledge of the risk of HIV infection, participant’s responses indicated infrequent and inconsistent condom use. Most participants did not use condoms during many of their sexual encounters. Even though most of the participants perceived themselves at risk, they continued to engage in unprotected sex. The HBM is based on the understanding that if an individual believes that a recommended health action will help them avoid an illness, then the action is beneficial and it outweighs the barriers. For example, an individual may overlook the cost of condoms and buy them for protection every time they have sexual intercourse in an effort to avoid getting infected with HIV. For this study, the HBM will be discussed in further in chapter 5 in terms of how adults can be guided to have a positive expectation if they choose to use condoms every time they have sex. For example, adults could reduce the rate of HIV transmission if they use condoms consistently. The HBM construct of cues to action is applicable in this interview item. Cues to action can be used as a prompt by an individual to remind them to use condoms every time they have sexual intercourse. Cues to action could be used as a theoretical framework to guide health care providers to make effective HIV interventions by identifying positive ways of encouraging condom use among adults ages 30-39 years old. I discuss this concept in more detail in Chapter 5. Table 6 presents some responses to Interview Item 3.

Table 6

*How Often Participants Used Condoms Before Becoming Infected With HIV*

Responses & themes	No. of participants	% of participants
Used condoms every time	0	0
Did not always used condoms	11	92%
Only when asked to use a condom	1	8%

*Note.*  $N = 12$

**Interview Item 5**

Based on your experience, can you describe for me what your sex life was like before you got infected with HIV? Responses to Interview Item 5 were related to the sex lives of the 12 HIV-infected adults prior to contracting HIV. Most participants described their sex lives in terms of being in relationships that did not require the use of condoms. Four of 12 participants (2, 9, 10, & 11) reported dating women at one point and men later in their lives. Other participants reported dating men and women at the same time or interchangeably. Five participants (1, 6, 8, 3, & 12) said that they were in relationships before becoming infected with HIV. Participant 1 commented:

You tend to get relaxed when you know about each other and you tend to trust more but, then later on, you find yourself having unprotected sex with this individual and that point you're not really thinking about it because, you felt like you've built up this long trusting relationship.

Key elements of this interview item included descriptions of being in relationships; MSM; homosexual lifestyle; "trusting the wrong people"; having partners who were living on the streets; dating women but getting HIV after "messing around with dudes"; first time away from home; "something about college." The HBM is discussed further in chapter 5 as the theoretical framework used to explain the different aspects of

behaviors described by participants. HBM could be used as a motivational guiding tool to encourage adults to practice safe sex and adopt healthy sex behaviors so that they can avoid the consequences of HIV infection. For example, adults can be motivated by incentives geared towards safe sex so that they can avoid getting infected with HIV. I discuss key elements related to Interview Item 5 in context to HBM detail in Chapter 5.

Table 7 presents some responses to Interview Item 5.

Table 7

*Sex Lives of Participants Prior to Contracting HIV*

Responses & themes	No. of participants	% of participants
In relationship	5	42%
Had one partner	2	17%
Dated both men and women	4	33%
Unknown	1	8%

Note. Participants ( $N = 12$ ) could provide more than one answer.

**Interview Item 6**

Based on your experience, describe what risky behavior may have contributed to your HIV infection. Responses to Interview Item 6 were related to the participants' involvement in risky behaviors that might have contributed to their HIV infection. Participants voluntarily shared their general experiences about these risky sexual behaviors. The major risky behavior reported by seven participants was engaging in unprotected sex. Other risky behaviors included having multiple sex partners. The use of drugs and alcohol was minimal. Participant 10, a 48-year-old man who had been diagnosed at age 30, stated, "Having sex without using protection. Trusting my dude. Like I said, I had a girl on the side, but I don't think she was risky."

The risky behaviors described by the participants can be important factors to future research and prevention intervention initiatives. The HBM construct of perceived benefits is applied in chapter 5 in context to prevention of HIV and other sexually transmitted illnesses. I discuss key elements of this interview item in more detail in Chapter 5. Table 8 presents some responses to Interview Item 6.

Table 8

*Involvement in Risky Behaviors That Might Have Contributed to HIV Infection*

Responses & themes	No. of participants	% of participants
Unprotected sex	7	58%
Drugs	2	17%
Drinking and smoking marijuana	2	17%
Multiple sex partners	2	17%
Oral sex	1	8%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

**Interview Item 7**

Based on your experience, describe what being infected with HIV at your age is like. Responses to Interview Item 7 provided insight into the lived experiences of the participants at their ages. Participants described how HIV had affected their lives in terms of their ages at the time of the study. The responses highlighted the participants' positive life experiences, negative life experiences, and normal life experiences with their HIV-positive status. Four (2, 3, 8, & 12) participants identified having negative experiences living with HIV. Participant 8 remarked:

A living hell. I mean, not making it sound dramatic or anything but, I mean it's a challenge. It's just a challenge for people to find a doctor that you're not being uncomfortable with. For the last about 5/7 years I had a doctor that was overseas 'cause I wasn't comfortable. I've been to clinics, where I don't feel comfortable.



Maybe there's some paranoia too with you being ... you probably think that people just look at the paper and see your name and they just like, oh they sometimes you think are they gonna ask somebody if they know you and everyone is gonna find out about you.

Six participants (4, 5, 6, 9, 10, & 11) identified having positive experiences living with HIV. Participant 6, a 46-year-old man who had been diagnosed at age 25, commented:

Since I'm older, and I know the resources it may be stronger. It may be stronger and make me to empower and teach younger kids. Like what I do now. I'm into like the ballroom scene, so what I do now I teach younger kids prevention and stuff like that. I have been teaching youth prevention for like five years. How to use condoms; and most of them homeless, and they come to ballroom scene.

That's where all the gay kids come, and we teach them health prevention. How to respect yourself; and you know drugs play a major role in the youth now as far as getting infected.

Another key element of this interview item was that being infected with HIV did not bother two of the participants. The positive aspect associated with having a normal life with HIV was credited to faith in God and prior experience with HIV among family members and friends. Two participants (1 & 7) said that their HIV status did not bother them. Participant 7, a 35-year-old man who had been diagnosed at age 22, said that having HIV did not bother him because he did not care. The HBM is applied in chapter 5

in context to how adults lived experiences with HIV such as treatment optimism and hard life can affect perceived severity. Table 9 presents some responses to Interview Item 7.

Table 9

*Lived Experiences of the Participants at Their Ages*

Responses & themes	No. of participants	% of participants
Positive experience	6	50%
Negative experience	4	33%
HIV at my age does not bother me	2	17%

*Note.*  $N = 12$

**Interview Item 8**

Based on your experience, describe how much your doctors and/or other health care providers like nurses talked to you about sex education and HIV prevention before you developed the infection. In response to Interview Item 8, participants provided insight into how much health care professionals had talked to them about sex education and HIV prevention. All participants except Participant 11 mentioned that they did not receive sex education or HIV prevention counseling from health care providers prior to diagnosis. This interview item was important because education is an important component in preventing the spread of HIV. Participant 1 stated:

I really didn't have any. Before I got infected, I had no doctors or nurses talk to me about HIV/AIDS. Before I moved back here to Atlanta, in Mississippi, my primary care physician when I went to him for my yearly physicals and all this other stuff, it was just that. It was no, have you had an HIV test. No, have you been tested for any STDs. It wasn't until I came here, and I just found out, so I've only been diagnosed in a year, it was around October of last year, and so it's new for me.

The responses to Interview Item 8 highlighted the need to support sex education and HIV prevention counseling. HIV education could help people to understand how HIV is transmitted and provide guidance on ways in which adults can protect themselves from infection, prevent new HIV infections, and reduce transmission rates. The responses provided by participants about how much sex education and HIV prevention they received from health care providers before they developed HIV infection could help understand their perceived risk of HIV infection. The HBM will be applied further in chapter 5 in context to primary prevention of HIV. For example, the HBM could be used to guide programs that aim to prevent HIV by increasing condom use. The HBM could also be applied secondary prevention of HIV. For example, HBM could be used to guide secondary prevention programs such as those that are geared to reducing HIV transmission caused by unprotected sex. I discuss different approaches and recommendations about HIV and sex education in more detail in Chapter 5. Table 10 presents some responses to Interview Item 8.

Table 10

*How Much Health Care Professionals Had Talked to Participants About Sex Education and HIV Prevention*

Responses & themes	No. of participants	% of participants
I did not receive sex education or HIV prevention from health care providers	11	92%
Not much sex education	1	8%

*Note.*  $N = 12$

**Interview Item 9**

Based on your experience, can you describe for me what might influence other adults to perceive that they are more at an increased risk of getting HIV infection? In

response to Interview Item 9, the participants offered suggestions on what could influence other adults to perceive that they are at increased risk of being infected with HIV. Participants shared a range of suggestions and thoughts. HIV-positive role modeling and practicing protected sex were consistent messages from the participants.

Participant 1 thought that an adult cannot be influenced and that it is a personal choice to perceive the risk of HIV infection:

That's a hard one, and the reason why I say that is because so many people, especially in the African American community, not only are we afraid to go to the doctor but a lot of people, its personal, it's a personal choice. And it's nothing that you, me, the doctors, mom, dad, nobody can really influence anybody to do anything because it's a personal choice of yours... It's all just personal choice I think.

Participant 2, a 38-year-old man who had been diagnosed at age 25, shared his perception about how stigma was a negative experience for adults who are HIV positive and made recommendations:

I think the thing is that we must get rid of the stigma. I mean that's the main thing. We really have to have some of these celebrities, these athletes, these high-profile political figures. We are not the only ones who are infected with HIV. There are some actors, there are some models, there are some celebrities, there are some politicians, and if they would stand up and hold up that banner and say listen, I'm living. It's not just Magic Johnson in this world. I think a lot of times, in the past these guys, Arthur Ash, Rock Hudson, Eazy E – because it was still this gay

disease so no one wants to tell anybody about it. When we get rid of the stigma and let people know we cannot get cancer by having unprotected sex but you can get HIV from having unprotected sex.

Three participants (4, 8, & 10) thought that using protection would influence other adults to perceive risk of HIV infection. Participant 4, a 35-year-old transgender who had been diagnosed at age 26, stated, “Always be safe, no matter what. Get tested regularly, both partners. No matter what.” Participant 8 suggested using condoms at all times. Participant 10 said, “Using protection. Not trusting anyone. Accepting you have it and not being reckless.”

Participant 12 suggested that HIV preventive medications should be made available to the public to reduce the risk of HIV infection. Participant 12 remarked, “You need to get a really cheap Truvada. Let people take Truvada. That’s the only way you’re gonna be able to do it. Just going ahead and publicizing safe sex is just not gonna do it anymore.”

The HBM is used to describe the populations most affected by the burden of HIV. The HBM is also used to measure the extent at which HIV infected adults perceived themselves to be at risk of HIV. The HBM construct of self efficacy can be used to increase the confidence among adults whose perception of HIV risk is low. Understanding the different approaches that can increase awareness of HIV risk might help to reduce the barriers and obstacles to effective HIV prevention strategies. I discuss the different approaches and recommendations about HIV risk in more detail in Chapter 5. Table 11 presents some responses to Interview Item 9.

Table 11

*Suggestions on What Could Influence Other Adults to Perceive That They Are at Increased Risk of Being Infected With HIV*

Responses & themes	No. of participants	% of participants
Personal choice	1	8%
Get rid of HIV stigma	1	8%
HIV positive adults should be role models	3	25%
Education	1	8%
Being safe, Using protection	3	25%
Creating awareness	2	17%
Use anti-HIV medications	1	8%

*Note.*  $N = 12$

### **Interview Item 10**

Based on your experience, can you describe for me, what your sexual beliefs and attitudes were like before you got infected with HIV? In response to Interview Item 10, the participants described their\ different beliefs and attitudes prior to becoming infected with HIV. The HBM suggests that personal beliefs about illness can predict the likelihood of adoption of recommended behaviors and influence sexual behavior prior to HIV infection. Two participants' (1 & 7) attitudes about sex were that they viewed it as something to do for the moment. Participant 1 said:

My sexual attitudes and beliefs? Before I got infected, sex was just something you do 'cause I'm single, so you know you're just living the life you meet somebody. That was my attitude towards sex before I got infected. I really didn't think about anything. I just did what felt good at the moment. It was just that, you're just like a free bird you don't really think about ok, I can get HIV or whatever.

Participant 7 stated:

I thought you have to be very messed up to get HIV. Didn't think I was that messed up. Didn't think I could get it at that time. I just liked dancing and dated females because I was young. Just having fun. Nothing messed up.

Six participants (2, 4, 7, 9, 10, & 11) said that they never thought they could get HIV. Participant 4 believed that "it couldn't happen to me. Never thought HIV would happen to me." I discuss sexual beliefs and attitudes about HIV in relation to the HBM in more detail in Chapter 5. Personal beliefs and attitudes about illness, sexual identity, sexuality, and sexual behaviors can influence personal threats of illness as well as the responses to recommended action. The HBM was used to understand the sexual beliefs and attitudes of participants before they got infected with HIV. In chapter 5, the HBM is used to understand sexual beliefs and attitudes of participants in relation to their short and long-term behaviors. Table 12 presents some responses to Interview Item 10.

Table 12

*Participants' Sexual Beliefs and Attitudes Prior to Becoming Infected With HIV*

Responses & themes	No. of participants	% of participants
Sex was something you do	2	17%
Dated both men and women	7	58%
Sex is personal and private	1	8%
Never thought I could get HIV	7	58%
Don't have sex	1	8%
Non-judgmental	1	8%
Not using condoms	1	8%
Using drugs	1	8%
Not promiscuous	1	8%
Feared being associated with gay	1	8%
HIV is a Caucasian disease	1	8%
HIV is a homosexual and bi-sexual men disease	1	8%
Thought they could get HIV	4	33%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

**Interview Item 11**

Based on your experience before you developed HIV infection, can you describe for me what your sexual lifestyles were? In response to Interview Item 11, the participants described their sexual lifestyles before HIV infection. This interview item is important because the responses provided deeper insight into the association between sexual behavior and risk of HIV infection.

Participant 1 said that because he was in relationships, he was not using protection:

Like I said before, I'm a relationship guy. I always started out by using protection but relaxed after I got to trust my partner even if I knew about the risks of not using protection. I am more cautious now after I got the infection.

Seven participants (2, 3, 6, 7, 9, 10, & 11) said that they dated women at one time and then started to date other men. Participant 2 remarked:

Like I said, I dealt with females for a long time and that was that part of the situation. When I was in Denver, I was very sexually active with women until I got to DC and then became very promiscuous with men.

Participant 5 revealed that he lived a homosexual lifestyle and shared his lived experiences as a transgender HIV positive adult:

I was homosexual. I only dated men. One person at a time. Always been transgender. A lot of guys be like dang girl you fine, I be like baby I'm a transsexual. He be like yea, and I be like yea, he say I don't care, I say ok. But I always let people know about me, I'm never trying to lead – I don't lead guys on because it's so many guys that



see me and think I'm a girl and I'm like no I'm a guy. I just have girls titties, and a butt, and body like a girl, but I say I still have my private. Boys be like wow. It don't bother me to tell people. A lot of the trannies don't like doing that. I love it. I let them know it's all muscle. They take it or leave it.

Participant 10 dated a man and a woman at the same time, noting, "Like I mentioned, I was dating a girl, and I had my guy on the side. I believe she had no clue about my other life. I wasn't using protection. Was trying to get all flavors." [laugh]

The revelations about their sexual lifestyles prior to infection revealed that the majority of the participants dated women before they started dating men and having sex with them. A few participants (1, 5, 8, & 12) shared that they had always preferred dating men. Some participants (2, 4, 10, & 11) acknowledged that they had had been involved with multiple sex partners before becoming infected with HIV. The HBM construct of perceived risk was used to understand the sexual lifestyles and attitudes of adults because this could help reduce the magnitude of the HIV epidemic in Atlanta and lead to better strategies for prevention. I discuss key elements related to Interview Item 11 in more detail in chapter 5. Table 13 presents some responses to Interview Item 11.

Table 13

*Participants' Descriptions of Their Sexual Lifestyles Before HIV Infection*

Responses & themes	No. of participants	% of participants
Relationships and no protection	1	8%
Promiscuous/multiple sex partners	4	33%
Tranny chaser	1	8%
Homosexual lifestyle	1	8%
Dated females then preferred men	7	58%
Always dated men	4	33%
Using drugs	1	8%
Did not use condoms	2	17%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

**Interview Item 12**

Based on your experience, do you think that health education for HIV/AIDS prevention from health educators like public health professionals can help to reduce the burden of new HIV infection among adults your age in Atlanta, Georgia? In response to Interview Item 12, the participants offered suggestions on ways that health education could reduce new HIV infections. Participants offered perceived benefits of health education, such as how education could influence youth to make good choices.

Five participants (1, 2, 4, 6, & 10) believed that health education could reduce the burden of new HIV infection. Participant 6 stated, “Well, the more people know the better for us all, especially the youth. They need to be empowered, and education will help them to make good choices and have more resources.”

Five participants (5, 7, 9, 11, & 12) believed that health education would not reduce the burden of new HIV infection. Participant 11 said, “I don’t think they can. I think it starts at home, and then goes beyond home by your belief system, your religion and stuff like that.”

Participant 3, a 45-year-old man who had been diagnosed at age 34, believed that those who are HIV positive should provide health education to reduce the burden of new HIV infection. He commented, “And I say that we are responsible – the people who know about their HIV status and care, share a hell of a responsibility, one to me, is to get the message out.” Participant 8 believed that health education will be effective only if health care providers are trained:

But I think the people who are in healthcare and whether you're a receptionist or whether you are a doctor or a nurse, it's for you to commit to educate their staff to know about confidentiality and know about things like that. And not necessarily, if you know somebody who has it don't think that the level of comfort that you have with that person that have it, that don't expect that I am supposed to be at the same level you are in terms of ....So, it's just ... I think for me it's more professionalism and more confidentiality in terms of protecting me as a person and if I come there and you're a healthcare provider then I should feel comfortable in coming there and knowing that I'm not gonna think that my whole business will be on the street.

Participant 12 asserted that only HIV preventive medicine or vaccines will help to reduce or prevent the burden of HIV:

Just going ahead and giving health education is not gonna do it. Not anymore. I think they need to start somehow providing Prep for the general public. The culture has changed. Telling people to use condoms and such won't work cause people aren't just using condoms anymore. We just need to spend money on getting the vaccine because that's just the only way to stop HIV. We need to figure out how to get Truvada into the public.

The participants' responses could help HIV educators to discover their failures and recognize their limited knowledge on the different approaches to HIV prevention. Analysis of the responses to this interview item could provide insight into the type of training needed for HIV educators. The HBM is used to understand the participant's

belief in the efficacy of health education and how the recommended health actions could help to reduce HIV infection in Atlanta. In chapter 5, the HBM has been applied in defining the action to take (how, where, when to enhance health education), clarify the positive effects to expected from providing health education, and describing evidence of effectiveness of health education. Table 14 presents some responses to Interview Item 12.

Table 14

*Ways That Health Education Could Reduce New HIV Infections*

Responses & themes	No. of participants	% of participants
Health education can reduce new HIV infection	5	42%
Health education will not reduce HIV infection	5	42%
Health education and awareness by HIV positive adults will reduce HIV infection	1	8%
Health education with confidentiality training	1	8%
More research will reduce the burden of HIV	1	8%
Only HIV preventive medicine or vaccine will help prevent HIV and reduce burden	1	8%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

### **Interview Item 13**

Based on your experience, can you help me understand what your living experiences with HIV infection is like in terms of your sexual lifestyle now? Responses to Interview Item 13 revealed the lived experiences of the participants related to their current sexual lifestyles. The responses facilitated a comparison to the responses to Interview Item 11 that could provide more insight about the lived experiences of HIV-infected adults.

Five participants (1, 4, 5, 8, & 11) said they are more cautious about their sexual lifestyles. Participant 4, for example, stated, “Now I’m focused on being safe. Always using condoms. I’m not with this person and that person. Not moving around with several different people. And, like I said not being unsafe like before.”

Three participants (2, 8, & 9) said that they had not disclosed their HIV diagnosis.

Participant 9 commented:

But you know, I still haven't told my family that I am gay as well as I haven't told them I am positive. I don't share my business like that. I know they're not dumb. So, some might know. If you know, you know. If you don't, it isn't their business it's mine.

Three participants (1, 6, & 7) said that HIV infection did not stop them from enjoying life. Participant 7 remarked. "My sex life is good. I have my partner, and he is HIV positive, too. We support each other, you know. It's all a mental thing. You accept and decide to enjoy your life."

Two participants (8 & 12) had challenges maintaining relationships, and two were ashamed of people knowing that they were taking HIV medication. Participant 8 stated:

I can't maintain a good relationship; I have to lie in a relationship. I can't reveal this part of me because I am scared of [what] people might know about me or a whole different. I don't want it to be like this great, beautiful thing even though you can live a healthy life if that makes sense what I'm saying. I guess practicing more safe sex. And even like what I do, I have my medication in a separate bottle from my actual medication because I don't want people to see the bottle and say okay that's what I have.

The participants shared that they were more cautious in their sex lives after becoming infected with HIV. The participants responses could help to measure behavior change after HIV infection. The HBM construct of self efficacy has been applied for

training, guidance, and positive reinforcement that could support adults confidence in their ability to take the action of safe sexual lifestyles. The HBM is applied further in chapter 5. Table 15 presents some responses to Interview Item 13.

Table 15

*Lived Experiences of the Participants Related To Current Sexual Lifestyles*

Responses & themes	No. of participants	% of participants
More cautious with sexual lifestyle after HIV infection	5	42%
Has not disclosed HIV positive diagnosis	3	25%
HIV is not a death sentence	2	17%
HIV did not stop me from enjoying my life	3	25%
Not able to maintain relationships	2	17%
Low testosterone	1	8%
More sex	1	8%
Not sexually active	1	8%
Challenging living with HIV	3	25%
Ashamed of HIV medicine	2	17%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

**Interview Item 14**

Based on your experience, do you think that the risk of new HIV infection among adults ages 30-49 years is a perception problem? Can you describe how this contributes to new HIV infections? Responses to Interview Item 14 provided insight into whether the participants thought that the risk of new HIV infections among adults ages 30 to 49 years was a perception problem. Half of the participants thought that it was a perception problem. This finding could help to assess whether adults' HIV risk perceptions can predict subsequent sexual behaviors. Four participants (1, 3, 4, & 12) thought that HIV risk was not a perception problem. Participant 1 commented:

I don't think HIV is a perception problem. Like I said, I think with HIV prevention or even people, when you think about the risk of HIV, it's not perception. I don't believe that it's perception because, like I said, people, no

matter what they perceive the disease to be; no matter what they think, people are still gonna take risks. All day, everyday; people are gonna take risks. A lot of people, they may use a condom on Friday, but Saturday they are having unprotected sex. The same thing with a lot of guys and friends that I have, they are on Prep. They still have unprotected sex because they think that Prep is the wonder drug and I can go and have unprotected sex with as many guys as I want, as many females as I want and, you know, that's what the medication is for. But no, that's not true, you know. Prep doesn't prevent you from getting HIV. It's a means of protection and prevention but it's all about personal choice because, you know, it just all goes back to personal choice. Yeah.

Six participants (5, 6, 8, 9, 10, & 11) thought that HIV risk was a perception problem. Participant 5 stated:

A lot of people think it's a gay thing. They think it's still homosexual activity and only gay people gets that. And they feel that every gay is ignorant and simply minded. And the younger ones dying quicker than us older ones now. They feel as though they untouchable. Having sex with this guy that guy, and a lot of them out there doing drugs. And prostitute for drugs.

The participants shared their personal feelings whether the risk of acquiring HIV was a perception problem based upon their own experiences. Analysis of the responses to interview item 14 is interpreted according to the HBM construct of perceived risk in Chapter 5. The HBM is applied in personalized and individual perceptions of HIV risk

based the participants beliefs and behaviors. Table 16 presents some responses to Interview Item 14.

Table 16

*Participants' Thoughts That the Risk of New HIV Infections Was a Perception Problem*

Responses & themes	No. of participants	% of participants
HIV risk is not a perception problem	4	33%
HIV risk is a perception problem	6	50%
HIV risk is more than a perception problem	2	17%

*Note.*  $N = 12$

**Interview Item 15**

Based on your experience with the HIV infection, describe for me what regrets you have, if there are any. Responses to Interview Item 15 identified any regrets that the participants had about their HIV infection. Participants who had regrets shared a wide range of negative experiences, including not loving themselves, not making sound decisions, not using protection, becoming infected with HIV, and understanding the impact of their HIV diagnosis on their families, among other consequences. Three participants (5, 6, & 7) expressed that they had no regrets about their HIV infection. Factors associated with not having regrets about their HIV diagnosis included family support, faith in God, supportive partners, effective HIV treatment, and receipt of Social Security benefits. Participant 6 said:

Well, I don't have no regrets. The reason I don't have no regrets is because I come from a religious family. My mom says it's the Lord's will. He put you in certain situations you're gonna be able to help others. So I don't have no regrets.



Four participants (1, 4, 8, & 11) regretted not using protection. Participant 11 stated:

If I could do it all over again, I would have had protected sex or no sex in college, when I was trying to get my degree. And I was trying to pledge fraternity, and all that stuff so I was doing what seem to be cool at the moment. And if I could take that moment back in time, I would have abstained from certain people. And I kinda knew these certain people were kinda high risk because they were doing stuff with certain people, out in the open too, so. But I took a chance and now this.

Two participants (2 & 12) regretted how their HIV diagnosis affected their families. Participant 12 commented:

Oh, I mean, it's just regrets. It has impacted my life in every category possible, from relationships to family to everything. Especially with my family. Well, I mean, when I told them it was just, you know, they had the worry and you know it caused excess worry in the family. Cause I told them all at the same time. Something else to deal with. So it was pretty impactful. Now my family has more things to worry about because of my health situation.

The responses to Interview Item 15 are interpreted in the context of the HBM in Chapter 5. In addition, the participants' feelings about the social consequences related to their HIV infection are analyzed and interpreted in the context of the HBM in Chapter 5. When sharing their regrets, the participants expressed more regrets related to social consequences than medical consequences. Social consequences included not being able

to have a family, not being able to maintain relationships, and causing their families pain and worry. The HBM construct of perceived severity was used to interpret participant's perception of how the consequences of having HIV infection affected their lives and if they think it was worth avoiding the disease. Chapter 5 covers more detail in relation to interview item 15. Table 17 presents some responses to Interview Item 15.

Table 17

*Regrets That the Participants Had About Their HIV Infection*

Responses & themes	No. of participants	% of participants
No regrets	3	25%
Regret not using protection	4	33%
Regret how HIV affected their families	2	17%
Not having sex education before HIV infection	1	8%
Not loving himself	1	8%
Telling his family	1	8%
Regret getting HIV infection	2	17%
Regret not having a family	1	8%
Regrets how he told his family	1	8%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

### Themes

For this study, I derived the themes based upon the criterion that they had to have at least six similar comments (or coded data) mentioned by other participants during the interview sessions. Textual data in the transcriptions had to be discussed repeatedly by individual respondents (frequency) and by different respondents (extensive) to be considered a theme. I identified ten themes from the analysis of the interview transcriptions. All six constructs of the HBM are used in chapter five to interpret the ten themes. The HBM construct of perceived risk was used to understand participants belief about their chances of getting HIV infection. The HBM construct of perceived risk was also used to understand the different aspects of population perception of risk and how the

low risk perceptions can be increased. The HBM construct of perceived severity was used to analyze participant's belief about the seriousness and consequences of HIV infection. The HBM construct of perceived benefits was used to analyze participant's belief on how effective a recommended health action could be in reducing HIV infection and transmission. Perceived benefits was applied to clarify the benefits that could be gained if an individual pursued the advised health action. The HBM construct of perceived barriers was used to analyze participant's perception about how costly the recommended health behavior would be. The cost of the recommended health action can influence a person not to change their health behavior. Health care providers providing services can reduce barriers for a recommended health action by providing incentives such as free condoms. The HBM construct of cues to action was used to analyze the triggers that can encourage participant's to perform the recommended health action. Triggers that can help a person make the decision to perform a health action may include post card reminders. The HBM construct of self-efficacy was used to analyze how confident the participant's was to successfully perform the recommended health behavior. For example, HIV mentors and positive models can provide encouragement to HIV positive persons in treatment compliance. Table 18 provides an extended summary of the result and themes.

Table 18

*Summary of Responses and Themes*

Themes	No. of participants	% of participants
Negative feeling when told of HIV positive diagnosis	11	92%
Knowledge about HIV risk prior to infection	8	67%
Believed they could not get HIV	6	50%
Did not always use protection	11	92%
Messing with dudes-homosexual lifestyle prior to infection	10	83%
Did not receive sex education or HIV prevention from health care providers prior to HIV infection	11	92%
Health education can reduce HIV infection	7	58%
Positive experience living with HIV infection	8	67%
Black culture	6	50%
HIV risk is a perception problem	6	50%

*Note.* Participants ( $N = 12$ ) could provide more than one answer.

### Summary

The purpose of this phenomenological study was to understand the lived experiences of HIV-infected adults ages 30 to 49 years in Atlanta, Georgia, by gaining their perceptions of risk prior to contracting HIV. The participants were recruited from and interviewed at the ID Group of Atlanta. A phenomenological approach was used to identify 10 themes that were identified from the data analysis process and in context to the HBM. The qualitative data analysis was completed using NVivo v.10. The data analysis revealed ten themes constructed from common responses among from the interviews.

Chapter 5 discusses the findings from the study in context to the RQ, the responses to the interview items, the limitations to trustworthiness, recommendations for further research, impact for positive social change, and the implications of HBM as the theoretical basis of this study.

## Chapter 5: Discussion, Conclusions, and Recommendations

### Introduction

Atlanta ranked number one among all other U.S. cities for new HIV/AIDS cases in 2013 (CDC, 2015a). The high rates of HIV and HIV/AIDS infections in Atlanta, Georgia, continue to raise concern among stakeholders. Data from the GDPH (2014) indicated that Georgia ranked fourth in 2011 with new HIV diagnoses. In 2012, Georgia had 50,436 HIV-infected persons; in 2005, it had 33,025 HIV-infected persons (GDPH, 2014). In 2012, Georgians ages 30 to 39 years and 40 to 49 years accounted for the highest number of new HIV infections in the state (GDPH, 2014). There is a need to understand the HIV risk perceptions of HIV-infected adults ages 30 to 49 years old in Atlanta because the city ranked number one among all other U.S. cities for new HIV/AIDS cases in 2013 (CDC, 2015a). Understanding the populations that are most at risk of HIV could help to reduce disparities by ensuring that those who are most vulnerable are effectively reached. Furthermore, research-oriented strategies could help to define the populations that are at most risk of HIV and hence reduce the infection rates in those specific groups (CDC, 2015a). I conducted this study to understand the HIV risk perceptions among HIV-infected adults ages 30 to 49 years in Atlanta, Georgia. This study is important because the results will provide deeper understanding about the burden of HIV and could help to improve in targeting and implementation of prevention programs.

The GDPH (2014) also reported that the prevalence of HIV is high in four counties in Georgia that are in close proximity to each other. Gwinnett, Fulton, Clayton,

and DeKalb counties account for 60% of Georgia's HIV data, and all four counties are located within 187 square miles of downtown Atlanta (GDPH, 2014). For this reason, I focused on asking questions to persons in the geographic area that was most important. According to the CDC (2015a), research findings on the geographic distribution of disease and at-risk populations reveal profound disparities in health and are used to guide the allocation of resources. For example, the findings of this study showed that majority of the participants never received HIV education before they got infected with the virus. Therefore, these findings could be used to allocate funding to HIV education agencies in Atlanta area. The higher annual rate of infection within the four counties is caused by a high percentage of IDUs and MSM, along with a high level of poverty (Sullivan et al., 2014). The literature review indicated that no research has been conducted to understand the risk perceptions and lived experiences of HIV-infected adults ages 30 to 49 years in Atlanta, Georgia. The literature review also showed that adults ages 30 to 49 years in Atlanta, Georgia, have suffered a significant burden of HIV infection. This study examined the main factors indicated in the literature review and their association to the perceptions of HIV risk among HIV-infected adults ages 30 to 49 years old in Atlanta, Georgia, thereby addressing the gap in the literature, creating awareness, and providing a basis for future research on preventive measures to reduce HIV infection in Atlanta, Georgia.

### **Summary of Key Findings**

Homosexual lifestyle and unprotected sex were the main risk factors identified for new HIV infections among adults ages 30 to 49 years old in Atlanta. Eleven of the 12

participants in the study were Black; one was White. The racial disparity among HIV-infected persons in Atlanta was demonstrated by the findings. Ten participants were men, and two were transgender (i.e., male to female [MTF]). The only participant who was not sexually active was transgender (MTF). Five participants perceived the HIV diagnosis as a death sentence. Eleven participants did not have positive feelings when first diagnosed as HIV positive. Only one participant (transgender MTF) took her diagnosis well. Even though eight of the 12 participants knew about the risk of contracting HIV, six did not perceive themselves to be personally at risk prior to becoming infected. Seven participants did not always use condoms before they became infected with HIV. Four dated women first and then men before they were infected with HIV. Seven participants identified unprotected sex as the risky behavior that might have contributed to their HIV infection.

Eight participants were using their HIV diagnosis to mentor others. Since the HBM is based on motivating people to take action, mentoring is a critical part of HIV education aimed at reducing HIV risk behaviors (Janz & Becker, 1984; Rosenstock, 1974). The HBM has been effectively applied as a theoretical basis for several HIV education program such as prevention interventions (Glanz & Bishop, 2010). Eleven participants did not receive sex education or HIV prevention counseling from health care providers. Several participants said that health education alone cannot reduce the number of new cases of HIV infection. The HBM implies that a person could perform a preventive action after an evaluation of how seriously an illness could negatively affect them. (Janz & Becker, 1984; Rosenstock, 1974). Some participants noted that HIV prevention strategies such as

Truvada for PrEP can be an effective method to reduce new HIV infection when compared to health education. Five participants became more cautious with their sexual lifestyle after HIV infection. Six participants thought that HIV risk was a perception problem. According to the HBM, beliefs about the risk of disease infection and the benefits of screening are strongly correlated with treatment compliance (Rosenstock, Strecher, & Becker, 1988). Most participants wanted HIV health care providers to be trained on issues relevant to confidentiality, privacy, health literacy, sensitivity, and cultural competence.

### **Interpretation of the Findings**

Ten themes were identified from the analysis of the interview responses. Key findings are interpreted through the lens of the HBM as the theoretical basis for this study. I used the HBM as a framework to analyze the data. The HBM was used to interpret the results for this study because it serves as a framework to better understand the participants' perceptions in relation to all six constructs. All six constructs of the HBM were aligned with the RQ. The themes revealed the HIV risk perceptions prior to HIV infection and the lived experiences of HIV-infected adults.

### **Perceived Risk**

The HBM construct of perceived risk refers to how individuals perceive their chances of getting a disease (Glanz, Rimer, & Viswanath, 2008). Based upon the responses, eight of 12 participants were knowledgeable about HIV risks. Six participants knew that they were at risk of HIV infection. The participants understood such HIV risk factors as unprotected sex, drug use, casual sexual encounters, multiple sex partners, and



trust in the wrong people. One participant thought that HIV was a gay disease, so he did not perceive himself to be at risk of infection because he was dating women at that time and then dated men later in his life. Another participant thought that HIV was a White disease and thought he was not at risk because he was Black. Six participants felt that they were not personally at risk of HIV infection. Reasons included being in monogamous and concurrent relationships where they assumed faithfulness and believing that HIV was only for “very messed up people” and “crackheads.”

Five participants were more cautious about their sexual lifestyles after receiving their HIV diagnosis. Some participants expressed concern about their risk of being reinfected with higher viral loads and contracting other STDs. Other participants expressed concern about the risk of infecting their sex partners. Eleven participants did not always use protection. Ten participants associated their HIV infection with “messing with dudes” or engaging in a homosexual lifestyle prior to infection.

These findings confirm the peer-reviewed literature that MSM is one of the major contributing factors to the HIV epidemic in Atlanta (Hixson et al., 2011). The findings also disconfirm Renchers’ (2012) assertion that poverty and injection drug use are major contributing factors of HIV risk in Atlanta. Out of the twelve participants, ten of them did not associate their HIV infection to drug use.

### **Perceived Severity**

The HBM construct of perceived severity refers to how a person perceives the seriousness of getting infected with a disease and the consequences of contracting that illness (Glanz, Rimer, & Viswanath, 2008). Perceived severity in the context of this study

further refers to the HIV positive individual having a limited perception about the seriousness of not complying with the recommended treatment. A person's perception of severity may include medical consequences such as becoming disabled or dying from the acquired disease. A person's perception of severity may also include social consequences such as poor or lack of social relationships and/or negative experience in family life due to the disease. Five participants perceived HIV as a death sentence by expressing that they thought that their lives were over after becoming infected. Some participants perceived the HIV-positive diagnosis to be the end of the world. Other participants feared the stigmatization that they would experience from their diagnosis. For example, one participant stopped taking his medication because he feared that his coworkers would find out he was HIV positive. Other participants expressed fear of the large number of medications that they would have to take to treat HIV. Other participants were concerned that the frequency at which they were required to take HIV medication would cause people to know about their HIV infection status. Two participants associated their HIV-positive status to difficulty finding love and challenges of being in relationships. Other participants feared that noncompliance with HIV medication would put them at risk of other diseases such as meningitis and lead to early death.

The findings of this study are consistent with the literature review. Grov et al. (2010), for example, asserted that the stigma of HIV/AIDS is one of the additional challenges facing HIV-positive adults. Nyamathi et al. (2013) suggested that future HIV interventions focus on decreasing internalized and enacted stigmatization in an effort to improve treatment outcomes. Barclay et al. (2007) and Beer et al. (2014) further

suggested the inclusion of education in self-efficacy and medication management for HIV-positive individuals when developing and implementing HIV preventive strategies.

### **Perceived Benefits**

Effective decision making involves considering all barriers and benefits. The HBM construct of perceived benefits refers to people's perceptions of the value of performing a new health behavior if it will reduce their risk of getting an illness. For example, if a person believes practicing protected sex outweighs the cost of condoms, then they are likely to use protection to avoid getting HIV infection. Perceived benefits reported in this study consisted of participants expressing that HIV-infected adults should disclose their HIV positive status so that their sex partners could protect themselves from infection and reduce their HIV risk. Three participants said that practicing safe sex would reduce the risk of HIV and other STD transmission. Two participants suggested that making PrEP as an HIV preventive strategy available to the public would prevent and reduce the spread of new HIV infections. Other participants said that they were using their HIV-positive status as a role model to encourage other HIV-infected persons to take their medications and to educate those who were not HIV positive about the risks. These findings demonstrate how the perceived benefits of reducing HIV can influence both HIV-infected and noninfected persons in practicing HIV preventive measures.

### **Perceived Barriers**

The HBM construct of perceived barriers means that an individual's perception of the obstacles and/or challenges that may hinder them from performing a recommended health action. Perceived barriers include an evaluation of the values of all benefits against

all costs. For example, a person may weigh the effectiveness of the recommended health action against the perceptions that it may be expensive, unpleasant, dangerous, time-consuming, or inconvenient. Participants' perceptions of the challenges to adopt HIV preventive measures included statements that HIV preventive medicines were very expensive, condoms were expensive, condoms reduced sexual pleasure, and concern about suffering stigma and discrimination if they disclosed their HIV-positive status. One participant said that Black culture did not trust health care providers and consequently did not seek health education, resources, or treatment. Another perceived barrier expressed by six participants was that HIV risk was a perception problem and people did not take preventive measures because of their beliefs. Eleven participants did not receive sex education or HIV prevention counseling from health care providers prior to HIV infection, factors that might have contributed to their risk of acquiring the virus. Seven participants felt that health education could reduce HIV infection rates. Three HIV-infected adults did not disclose their HIV-positive diagnosis to their sex partners, families, employers, or health insurance companies because they feared rejection, stigmatization, and discrimination. These findings confirm results from the literature that HIV-related stigma exists when HIV-infected persons receive social resources and support from close friends and family (Galvan et al., 2008).

### **Cues to Action**

The HBM construct of cues to action refers to the stimulus that triggers a person in the decision-making process leading them to act on a recommended health action. Cues to action include both internal prompts and external factors to perform an action.

Internal cues may include perception of symptoms, pain, fatigue, or a negative change in bodily state. External cues may include reminder postcards to use condoms, advice from mentors, illness of friend, death of a family member, health warning labels, health fairs, HIV mass media campaigns, social influence, and newspaper articles. Participants' expressed both internal and external cues to action. For example, one participant was hospitalized when he became very ill with meningitis because he had stopped taking his HIV medication (internal cue). The main reason why the participant stopped taking his medication was fear of stigma-related discrimination in his workplace. Another participant expressed external cues to action when he stated that he had gone to several funerals of friends who had died from HIV complications.

Internal and external cues instigated the decision-making process for the participants to be more cautious in their sex lives after receiving their HIV diagnosis and to act on advised preventive actions, such as disclosing their HIV-positive status to their sex partners, using condoms as a preventive measure, reminding sex partners to use protection to avoid transmission of other STDs, and taking medications recommended by health care providers to maintain good health. These findings confirm conclusions drawn by Stephenson et al. (2011) that voluntary counseling and HIV testing are positive empowering tools that encourage individuals to act on the recommended health action.

### **Self-Efficacy**

The HBM construct of self-efficacy refers to an individual's level of confidence that they are able to successfully perform the new health behavior. Self-efficacy directly relates to whether a person is capable of performing the desired behavior. Several

participants expressed confidence in their ability to use their HIV-positive status successfully. For example, eight participants stated that they had had a positive experience living with HIV. Some of the desired behaviors that the participants mentioned included using protection in a consistent manner to avoid infecting others or getting other STDs. Other participants said that they would take their medication as required to maintain good health and to encourage others to be compliant. Several participants believed that the positive role modeling of HIV-infected adults would decrease the rate of new HIV infections and motivate others to adhere to treatment protocols and maintain good health.

Some participants were confidently using their HIV experience to counsel and motivate others. Others participants were using their HIV-positive status to extend awareness about the disease. Findings were consistent with conclusions by Barclay et al. (2007) and Beer et al. (2014) that future HIV interventions should include education and counseling about self-efficacy and medication management for individuals of different ages and ethnicities who are HIV positive.

### **Limitations of the Study**

Some limitations were identified in this study. Participation was limited to HIV-infected adults ages 30 to 49 years old who were living in Atlanta, Georgia, at the time of the study. The study was limited to metro Atlanta area because the city ranked number one in 2013 for new HIV/AIDS cases among other cities in the United States (CDC, 2015a). Therefore, the results of this study cannot not be generalized to HIV-infected adults outside of these age set or those who live in other locations. This study was limited

by its qualitative design and the phenomenological approach used to guide the face-to-face interviews. The validity of the collected data was entirely dependent on the honesty of the participants. Other HIV-infected adults living in the Atlanta metro area might not have shared the same perceptions as those who participated in this study.

### **Recommendations for Further Study**

The purpose of this study was to understand the lived experiences of HIV-infected adults ages 30 to 49 years with respect to their perceptions of risk prior to developing HIV and then after contracting HIV. Recommendations for further research were identified from the discoveries made through the data collection and analysis processes, the discussion process, and the HBM theory that guided this study. The HBM was developed by a team of psychologists in the 1950s to understand why there was a low response rate for a Tuberculosis screening program developed for adults. Since then, the HBM has been applied for over three decades in practical interventions across a wide range of health behaviors (Orji, Vassileva, & Mandryk, 2012). Public health preventive strategies that are based on theories have shown to be more effective compared to interventions developed on the basis of assumptions (Glanz et al., 1997).

Eleven participants reported that they did not receive sex education or HIV prevention counseling from health care providers prior to becoming infected with HIV. I recommend that health care providers develop and implement a protocol to ensure that patients receive sex education or HIV education during visits when seeking care as one way to reduce the rates of new HIV cases. Researchers and health practitioners have used the HBM to design behavior change interventions that are focused on promoting healthy

behavior (Orji, Vassileva, & Mandryk, 2012). Most participants expressed that they could not trust or feel comfortable with health care providers because of previous experiences of stigma associated with receiving care. The HBM has been used effectively to understand different health behaviors and define risk levels in specific populations (Janz & Becker, 1984). The participants recommended that all HIV health care providers be trained in issues regarding confidentiality, privacy, health literacy, sensitivity, and cultural competence to ensure better management of HIV patients. The six HBM constructs could be used to develop training, guidance, and positive reinforcement for health care professionals when providing service and care to HIV infected persons (Glanz & Rimer, 1997).

The sample comprised 11 Black participants and one White participant. This imbalance was evidence of the major gap in HIV and racial disparities. For this reason, I recommend that HIV health care professionals develop and implement a framework of individual, community, societal, and environmental levels to understand the complexity of HIV and racial disparities. All HIV/AIDS health intervention programs and preventive approaches also must incorporate race and ethnicity, geographic location, and social factors related to MSM. I recommend that future researchers study the impact of community factors to gain more insight into HIV risk factors, particularly in metropolitan and inner-city areas. The personal perception of risk has been found to be an important perception in promoting the adoption of healthier behaviors (Orji, Vassileva, & Mandryk, 2012). People are more motivated to adapt healthy behaviors if they believe they are at risk to a particular negative health outcome (Rosenstock, 1966). For this reason, health



care professionals should invest in implementing programs that include populations that are disproportionately affected by HIV to reduce disparities by ensuring that those who are most vulnerable are effectively reached.

### **Implications for Social Change**

The potential impact for positive social change in this study focused at reducing the rates of new HIV infections and HIV-related stigma, and addressing HIV racial disparities through individual, relationship, familial, community, group, and organizational interventions as well as public health policy. One major need expressed by the participants was sensitivity, confidentiality, and cultural competence training for HIV caregivers, health care professionals, and other service providers. One participant said that he overheard his HIV-positive diagnosis being discussed by nurses and doctors in the hallway while he waited in the patient room. Another participant said that he had been going out of the country to receive HIV treatment and care because he could not find a health care facility where he felt comfortable. Another participant said that an employee of the facility where he got his HIV diagnosis told his friends about his status.

Participant 3 commented:

You just gave somebody a job, that's really pushing away people more you know why? They get on the phone, they gossiping, telling people your HIV diagnosis...The same way police officers or firemen have to take sensitivity classes, people need to be more sensitive and educated, about the LGBT community.

Another participant said that his mother wanted to buy separate dinnerware for him when she found out about his HIV-positive status. Sensitivity, confidentiality, and cultural competence training will improve the treatment efficiency toward underrepresented and highly stigmatized populations such as MSM and transgender populations. Sensitivity training for families, communities, and health care providers will help to reduce the stigma and silence as barriers to HIV health interventions, increase awareness of HIV/AIDS risk factors, and strengthen communication between HIV health care providers and MSM and transgender patients.

The results also showed that MSM and involvement in unprotected sex were the major factors contributing to new HIV infections in respondents. Policies and health interventions should focus on HIV risk education, behavioral skills training, sexual assertiveness training, and lifestyle changes to reduce or prevent HIV. Such HIV prevention policies and interventions could help to increase the rates of condom use among MSM and other populations affected by HIV.

Seven participants believed sex education can reduce HIV infection. Sex education and HIV education initiatives aimed at positive social change should be based on a combination of different levels, that is, individual, relationship, familial, group, organization, societal, and policy. All of these levels should be aligned so that they can facilitate dialogue and feedback between and among HIV caregivers, health care professionals, and other service providers to achieve common objectives.

The findings will encourage dialogue that will provide a broader view and further insight into different types of sexual orientations that experience HIV-related stigma.

HIV education also could increase knowledge of different sexual orientations, reduce assumptions that MSM are gay or homosexual, and reduce HIV transmission rates. Sex education and HIV interventions could be implemented to protect individuals and develop public health policies that include approaches and interventions that focus on reducing HIV structural barriers at a larger level.

The HBM was used as the theoretical basis to guide this study. The HBM has been used to understand HIV risk perceptions and lived experiences, factors that influence the choices of sexual partners and personal variables, and the diverse settings of HIV. Theory-driven interventions have been effective in addressing populations who are disproportionately burdened by HIV. For example, unprotected sex and MSM lifestyle were identified in this study as the main factors affecting the rates of increased HIV infections. The HBM can be used to promote safer sexual behavior as an effective method of preventing HIV infection. For example, the HBM can promote action to change behavior related to individual personal beliefs.

### **Conclusions**

Despite the research, science based innovations, and the availability of effective prevention interventions, the HIV/AIDS epidemic continue to be a burden to our society in its third decade. Study findings showed that more than 67% of the participants possessed knowledgeable about the risk of getting infected with HIV. Despite their knowledge of HIV risk, 50% of the participants believed they were personally at risk of becoming HIV infected. Participant's shared that they gained their knowledge about HIV risk from different sources such as television; family members; neighborhoods; internet

sources; HIV health campaigns; rumors; and personal experience, such as the deaths of friends and family members who had been infected with HIV. Findings from the CDC and the literature review showed that HIV/AIDS prevention strategies that are evidence based have been effective in reducing risky behaviors that increase the risk for HIV infection (CDC, 2015a).

The data collected was from HIV infected participants who lived in Atlanta, Georgia at the time of the study. According to the CDC (2015a) HIV remains mainly an urban disease and Atlanta was among the cities most affected by HIV cases per 100,000 people in 2013. Majority of the individuals diagnosed with HIV lived in cities or urban settings highly where more than 500,000 people resided (CDC, 2015a).

Unprotected sex was identified by participants as the most common risky behavior that contributed to their HIV infection. The findings agree with the CDC's (2007) results that the most common method of HIV transmission is unprotected sexual intercourse. All participants including two transgender (MTF), identified their sexual preference partners as male. Study participation indicated that MSM in Atlanta are a heavily burdened subgroup for new HIV infections by transmission category. According to the CDC (2015a), MSM continue to suffer a significant burden of HIV and currently account for the highest new HIV cases in all races and ethnicities. In 2010, MSM accounted for 78 % of new HIV infections among men and 63 % of all new infections in the U.S. (CDC, 2015a). In 2011, male-to-male sexual contact was the main mode of HIV transmission for Black MSM and accounted for 72% of new HIV cases (CDC, 2014a). The conclusions from the CDC (2014a) were consistent with findings of this study

because 100% of the study participants shared they had male-to-male sexual contact and most of them did not use protection. Majority of the participants felt that sex education alone was not sufficient to influence behavioral change. For this reason, HIV preventive measures should combine approaches, such as sex education, positive HIV role modeling, interactions with trained professionals, use of social networks, campaigns, condom social marketing, policies, theories, and the availability of HIV preventive medications, as an effective method to help to reduce the risk of HIV infection. The HBM constructs were very useful in identifying individual behaviors associated with higher rates of HIV transmission. Theoretical frameworks such as the HBM should be used to provide guidance to HIV prevention interventions.

Evidence-based interventions at the local and national levels should be used to reduce racial and ethnic health disparities related to HIV infection rates. Factors affecting HIV disparities in relation to this study include race and/or ethnicity, geographic regions, and sexual preference or orientation. Future priorities should focus on identifying best practices relevant to individual, familial, organizational, societal, environmental, economic, and policy factors with the goal of reducing the risk of HIV/AIDS and minimizing negative life experiences for individuals who are HIV positive. Researchers and health care professionals should prioritize in planning and implementing effective HIV prevention programs, policies, and research that will reduce the incidence of infections and decrease health disparities. HIV prevention strategies should be focused on communities that are disproportionately affected by HIV. Individual, family, community,

and organizational levels should be considered during the planning, promotion, implementation and evaluation process of all HIV initiatives.

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## Appendix A: Letter of Permission to Use Interview Questions

06/30/2015

Title of the Authorized Work: HIV Risk Perceptions Among HIV Infected African American Adults 50 Years and Older

UMI Number: 3614513

I, Dr. John U. Nwankwo, the author of the Authorized Work, which was created on May 2014 (hereinafter as 'the authorized work'), agrees to authorize Esther Ashford to apply the authorized work, solely and exclusively for the purpose of completing her dissertation at Walden University. I hereby authorize her to use my study, in those sections where applicable and only, for non-profit purposes of completing her doctoral dissertation at Walden University, in the following areas:

- a. Interview questions from my study as applicable to her dissertation
- b. Quotations from my interview questionnaires as applicable to her dissertation

As the author of this study, I guarantee that the authorized work is done by me and has the right to authorize Esther Ashford the limited use of those sections of my study questions and quotations from my study interview questionnaires as may be applicable, solely and exclusively for the purpose of completing her doctoral dissertation at Walden University. Apart from this non-profit exclusive purpose as stated herewith; Esther N. Ashford is not authorized by me to use my study for any other purpose. The sections regarding contents usage of my work is hereby included in this letter of authorization.

This letter of authorization is addressed to:

Esther N. Ashford

Name of Signer (author): Dr. John U. Nwankwo (author electronic signature): John Nwankwo

Day/month/year: 02/07/2015.

I, Esther Ashford, have reviewed and agree to the above terms and conditions, and certify my compliance with my signature hereunder.

*E.ASHFORD*

## Appendix B: Letter of Cooperation from Community Partner

Dr. John Ouder Kirk, MD

Dear Esther Ashford,

Based on my review of your research proposal, I give permission for you to conduct the study entitled *HIV Risk Perceptions among HIV Infected Adults 30-49 Years Old in Atlanta, Georgia* within the Infectious Disease Group of Atlanta (IDGA). I am providing you with a Letter of Cooperation granting permission to access to interested study participants, facility use, and/or use of personnel time for your research purposes. I also give you permission to conduct a pilot study prior to the main study. The pilot study is a preliminary version of the main study and aims to test the effectiveness of the sample size, data collection methods, study resources, discover potential problems, and gain a better understanding in the different elements of the research process. Based on the experience from the pilot study, the principal investigator may make changes to the approach and design of the main study. The procedures for the pilot study include face to face interviews with three eligible participants. Eligible participants may be any gender including male, female, transgender, and others who are HIV infected persons; the HIV infected persons must have HIV diagnosis for at least 12 months; current residents in the Atlanta metro area (Fulton, Clayton, DeKalb, and Gwinnett Counties); 30-49 years old. Data collected from the pilot study will not be included in the main research study. Instead, the pilot study will foreshadow research problems and questions, highlight gaps and wastage in data collection, and identify broader and significant issues such as research validity, ethics, representation and researcher health and safety. In case there are any changes to the main study based on pilot study findings, you will submit IRB approval to proceed with the main study. You will provide me (Dr. John Ouder Kirk, MD) with a copy of Walden University institutional review board (IRB) letter of approval before the recruitment or data collection process.

As part of this study, I authorize you to provide recruitment flyers to the Infectious Disease Group of Atlanta clinical onsite staff who has volunteered in assisting in the recruitment process for your study. The clinic volunteer staff will not perform any other responsibilities other than handing and distributing the flyers to onsite patients. The clinical staff may also place the flyers in the patient examination rooms so that patients may pick them up in privacy. The clinic staff assisting with handing the flyers will not discuss or encourage HIV positive persons to participate in the study. Interested potential participants will contact the principle investigator (Esther Ashford) to schedule a date and time for the interview. The principal investigator will determine if the participant has met the inclusion criteria. The principal investigator will personally follow up with all potential participants who respond to the recruitment flyers. All eligible participants will sign a letter of consent. The consent form will be used to ensure that all participants are adequately protected. Part of the consent form will require that participants approval and agreement to be audio-taped during the interview session.

The process of data collection for this study will involve one-on-one interviews, storytelling, answering of open-ended questions and participants explanations of their personal perception as regards to the risk of HIV infection. If, clarity is needed, the principal investigator will follow-up with a telephone and use a non-directive interviewing to allow the participants the freedom to control pacing and subject matter of the interview. The researcher will record the information from the telephone interview by making hand-written notes. Results dissemination activities include providing a 1-2 page summary of the results to study participants who are interested the in the research findings. Research findings will also be shared in conference presentations for participants and others who choose this method. End-users such as clinical staff who volunteered and other organizations that could benefit by applying the research results will be invited to formal and informal social networks that will share information and provide study findings.

Individuals' participation will be voluntary and at their own discretion. Participants, who wish to withdraw from the study, may do so without any negative consequences. All study participants will be provided with an informed consent whereby the participant will be made fully aware of their right to withdraw from the research at any time in the process.

We understand that our organization's responsibilities include: Front office and clinical personnel who will assist in the recruitment process. The layout of the patient exam room will allow privacy for study interviews. The room size will allow for three chairs to be used by the principal investigator and the study participants. A computer monitor will be placed on the work surface and the PC will be mounted on the wall. The exam room spaces should be comfortable and private and provide positive distractions. The waiting lounge is designed for family or friends who may wait on the study participants. We reserve the right to withdraw from the study at any time if our circumstances change. Note: The partner site does not have its own IRB or other ethics/research approval process.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,

Dr. John Ouder Kirk, MD, Infectious Disease Group of Atlanta, LLC