

AFRICAN AMERICAN WOMEN LIVING WITH HIV  
AND THEIR NUTRITIONAL IMPLICATIONS

By

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Bachelor of Science in Nutrition emphasis Dietetics Texas

Woman's University

Denton, Texas

2017

Submitted to the Faculty of the  
Graduate College of the  
Oklahoma State University  
in partial fulfillment of  
the requirements for  
the Degree of  
MASTER OF PUBLIC HEALTH  
July, 2019

AFRICAN AMERICAN WOMEN LIVING WITH HIV  
AND THEIR NUTRITIONAL IMPLICATIONS

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## ACKNOWLEDGEMENTS

Firstly, I would like to thank my family, friends, and my partner. Coming to Oklahoma State University, hours away from home has been an adjustment however, their ability to support and love me never diminished. My parents have given me endless love, emotional, and mental support which I can never repay them for. I have experienced personal growth through receiving support and learning from others I have met during my graduate school journey. I want to also thank my mentor, Dr. Theresa Lindsay. She is part of the reason for the pivotal shift in my thinking concerning my abilities and self-advocacy. Now, I choose to realize my full potential and won't be afraid to bet on myself. Lastly, I would like to acknowledge and thank my advisor, Dr. Randolph Hubach, for allowing me to explore my interest and helping me every step of the way.

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Date of Degree: JULY 2019

Title of Study: AFRICAN AMERICAN WOMEN LIVING WITH HIV AND  
THEIR NUTRITIONAL IMPLICATIONS

Major Field: PUBLIC HEALTH

Abstract: HIV is still an epidemic. According to HIV.gov, more than 1.1 million people in the US are living with HIV and less than 14 percent know their status. The Southern states account for over 50% of all new HIV infections. Although there has been ongoing innovations in medicine and care, the statistics among the African Americans (AA) living with HIV continues to grow. In Oklahoma for example, the rate of Black males living with an HIV diagnosis is 3.5 times that of White males and the rate of Black females living with an HIV diagnosis is 6.8 times that of White females. Geographic isolation and poverty among societal factors increases this disparity. There is a continued need for research which focuses on AA women living with HIV for several reasons however the most important reason is that they account for over half of the heterosexual population living with HIV in the United States today. Complications related to HIV/AIDS is one of the leading causes of death among African American women. Historically, HIV research has focused on homosexual white men and the high-risk behavior such as unprotected sex and injection drug use. African Americans differ from other groups when it comes to risks factors due to socioeconomic vulnerability, such as poverty, and spending time in a detention facility particularly men. Due to the rise of incarceration of men, African American women are at a higher risk of acquiring HIV. After a diagnosis, African Americans have a low adherence rate to medication and diet leading to death. Many AA women living with HIV are unaware of how their diet can affect their immune health. As such, there is need to evaluate the barriers to proper nutrition education and nutritious food. Ultimately, such data will inform larger public health programming to be culturally relevant for this population.

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## CHAPTER I

### African American Women Living with HIV and Their Nutritional Implications

The Human Immunodeficiency Virus (HIV) is one of the largest epidemics in the current era (CDC,2018a) It is spread through contact with bodily fluids such as blood, semen, pre- seminal fluid, rectal fluids, vaginal fluids, and breast milk (CDC,2018a). HIV can also be spread by sharing syringes or needles. HIV can lead to the Acquired Immunodeficiency Syndrome or AIDS by attacking the body's immune system, particularly the CD4 cells which help the body fight against opportunistic infections. There are currently 1.1 million people living with the virus in the United States (CDC,2018b). After infection, the body will go through an asymptomatic phase of HIV, allowing the virus to become incorporated into the host cell DNA and slowly deteriorates the immune system (CDC,2018a). If left untreated, the virus can destroy the CD4 cells commonly used to fight off opportunistic infections, such as tuberculosis, leaving the body defenseless. Before the use of antiretroviral therapy, people infected with HIV could progress to AIDS within a few years due to the fast deterioration of the immune system (CDC,2018a). Today, antiretroviral therapy, if taken right away, can dramatically prolong the life of people living with HIV. Despite medical advances, about 24%-27% of HIV positive people are not aware of their infection (CDC,2018a). When the HIV epidemic first appeared, the primary group affected were gay and bisexual men. However, as time has passed, minority populations are most affected by the HIV epidemic, more specifically African Americans (CDC,2018b).Begin typing or pasting the

African Americans account for over half of the population living with HIV, however they make up only 13-14% of the United States population (CDC,2018b). Unfortunately, research focused

on cultural or racial populations is not widely funded. Most of the research related to medical, social, and psychological factors of HIV are produced from research targeted on White Americans. With that said, methods explored for prevention and treatment in these studies have been proven ineffective for racially diverse populations. Discrimination, poverty, inequality and other social conditions facilitate the spread of HIV among African Americans (Carmen et al., 2016). Furthermore, instability of relationships caused by economic stress, stigma, and incarceration also contribute to sexual partner mixing patterns that foster HIV transmission (CDC,2018c; Pellowski et al., 2014). Therefore, African Americans living with HIV are less likely to receive appropriate HIV care.

One of the leading causes of death among African American women (aged 20-54 years) is HIV infection (CDC, 2015). African American women account for over 50% of the heterosexual population living with HIV (CDC, 2015; Shrage, 2016). There are several reasons that directly and indirectly affect the high HIV prevalence and incidence rates. As the rates of incarceration among African Americans increased, HIV rates did the same. Stigma remains to be an important contributor to retention in care along with, stereotypes, and poverty among African American women (Sangaramoorthy, 2017; Shrage, 2016). These factors equate to late diagnosis and non-adherence to care. Care for HIV includes visiting the doctor, taking antiretroviral medication, and having a balanced diet.

Nutrition and food safety has an impact on everyone but, can affect a person living with HIV dramatically. Choosing healthy food options can keep the immune system strong and help one maintain a healthy weight. Malnutrition and HIV can lead to weight loss, muscle wasting and macronutrient or micronutrient deficiency (Krause, 2016). These factors can lead to a compromised immune system. Because of this, similar to those living without the virus, maintaining a healthy diet,

and adhering to food safety guidelines is imperative in order to reduce the risk of foodborne illness. A compromised immune system coupled with poor nutrition status can also slow healing processes, possibly speed up the progression of HIV, and worsen HIV viral load suppression (U.S. Department of Health and Human Services, 2018; Krause, 2016).

Food insecurity and lack of nutrition information are the biggest barriers to eating healthy for African American women with HIV. Residential racial segregation which heavily impacts food access and education, are the main causes of the mentioned barriers (William and Collin, 2001). This is problematic given that literature suggests there is a link is present between food insecurity and a lower CD4 cell count in people living with HIV (Kalichman et al., 2010). One of the ways to improve access is through better transportation; however, obtaining reliable transportation was a recurring barrier in literature. Lack of transportation disrupts medication adherence, doctor's appointments, and decrease the ability to go to grocery stores or supermarkets.

### Statement of the Problem

In the United States, African American women are not well represented in HIV prevention or HIV care. Although rates of HIV have decreased 20% between 2011 and 2015 among African American women, they still represent over 50% of the HIV diagnoses within heterosexual populations. Nutrition, as with many other illnesses, plays an important role and should be used as part of their treatment process.

### Purpose of the Study

The purpose of this study is to use transcendental phenomenology to seek a deeper understanding of the experiences of African American women with HIV along with nutritional

insufficiencies.

### Hypotheses

Since this study is utilizing a qualitative phenomenological approach, no hypotheses will be tested during the course of the thesis.

### Significance

In 2016, African American women accounted for 4,189 of the female heterosexual HIV diagnoses. Meanwhile, White women accounted for 1,032 cases and Latina women accounted for 1,025 cases (CDC-a, 2018). In 2014, African Americans make up 32% of the state's population, however they account for 68% of the people living with HIV in the state of Louisiana. (<https://aidsvu.org/state/louisiana/>). Statistics like Louisiana hold true for many states in the south such as Georgia, Texas, Mississippi and Florida.

Although recent reports of new HIV infections has declined among Black/African American women, they are still heavily impacted. According to the Centers for Disease Control and Prevention (CDC), one in 32 Black women will have HIV in their lifetime compared to one in 526 for White women and one in 106 for Latina women (CDC, 2018a). African Americans do not engage in riskier behaviors that increase the prevalence of HIV than other ethnicities, however, African Americans are up against complex factors that puts them at greater risk. Since most of the people living with HIV are Black men, Black women are at increased risk for contracting HIV. Along with a high chance of exposure to HIV with every sexual encounter, African American women are at high risk due to fear, stigma, discrimination, negative perceptions about HIV testing, and socioeconomic issues associated with poverty, limited access to healthcare, housing, and HIV prevention education as discussed in

Chapter 2 (Shrage, 2016). After HIV diagnoses, many women are not aware of how nutrition can help the compromised immune system. A person living with HIV with a poor diet can lead to an impaired immune system which makes the body unable to fight against HIV progression. The risk for opportunistic infections increases which leads to an increased nutritional need. With predominantly African American neighborhoods over crowded with fast food and liquor stores instead of grocery stores, it makes it difficult to acquire nutritious foods (William and Collin, 2001).

### Delimitations

Delimitations for this study include geographic location, HIV positive status, recruitment clinic location, African American race and female gender. In this study participants were recruited through organizations serving HIV positive individuals in Southern states. The delimitations will be determined by the demographics survey.

## CHAPTER II

AIDS was first recognized in 1981, and since has been a worldwide pandemic (CDC, 2018c). AIDS is caused by human immunodeficiency virus or HIV. This virus is spread through bodily fluids such as blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids, breast milk and sharing syringes or needles (CDC, 2018c). The HIV and AIDS epidemic was first introduced as a gay-related immune deficiency. This name was due to most of the cases of HIV were presented in men who have sex with men in Southern California (CDC, 2018c). After females were diagnosed with disease the CDC changed the name to Acquired Immunodeficiency Syndrome (AIDS) to represent the evidence that it was impacting various populations, including injection drug users (CDC, 2018c). Today, minority populations are most affected by the HIV epidemic in United States.

### **Severity of HIV/AIDS Among African American Individuals**

#### **HIV/AIDS in the United States and in Oklahoma**

Since the 1980's when HIV began to become prevalent, HIV treatment has advanced. Antiretroviral therapy can help a HIV positive person live a healthy life. ART reduces the viral load in the body thus reducing the chance of the virus being transmitted to a partner if it is taken consistently and correctly (American Psychological Association, 2012). In the United States, about one million people were living with HIV in 2015. About 45% of the people living with HIV live in the South (CDC, 2018b). In 2015, the age group with highest HIV diagnosis are 20 to 29

(CDC, 2018b). In 2016, HIV diagnoses among Black homosexual males were at 10,233 people, Latino homosexual males were at 7,425 people, and White homosexual males were at 7,390 people (CDC,2018b). In 2016, HIV diagnoses among Black heterosexual women were at 4,189 people, Black heterosexual men were at 1,926 people, White heterosexual women were at 1,032 and Latina women were at 1,025 people (CDC, 2018b). In 2014 HIV is the 8th leading cause of death for individuals aged between 25-34 and 9th for those aged between 34-44 in the United States (CDC,2018b).

In Oklahoma, the number of people living with diagnosed HIV in 2014 was 5,605. From number of people living with HIV, 82% were men and 18% were women (Aidsvs, 2014). Fifty- six percent of the people living with HIV in Oklahoma are White, 9% are Latino and 23% are African American (Aidsvs, 2014). African Americans had the highest rate of newly diagnosed HIV cases and people living with HIV in 2016 among all racial and ethnic groups (OK.gov, 2016). African Americans also had the highest death rate in 2016 at 4.1 deaths per 100,000 but accounted for only 13.3% of deaths in 2016 among all racial and ethnic groups showing HIV as a leading cause of death in this population (OK.gov, 2016).

### **HIV/AIDS in African Americans**

In 1981, African Americans accounted for approximately one-quarter of all new HIV infections (CDC,2018b; McNair, Prather, 2004). Seven years later, African-Americans surpassed White Americans in the number of new HIV infections (CDC,2018b; Morin, 2015). While the overall infection prevalence has declined by 10% 2010 to 2014, the African American gay and bisexual men, diagnoses increased 2% (CDC, 2018b). Among heterosexual HIV diagnoses in the United States, African American women account for more than 50% in 2015 (CDC, 2018b ; McNair, Prather, 2004). African American men represent 70% of new infections, therefore, 1 in 16 black men and 1 in 32 black



women will be diagnosed with HIV sometime in their lifetime (American Psychological Association, 2012; McNair, Prather, 2004). In 2015, the highest death rate from AIDS was among African Americans. Blacks/African Americans make up for 14% of the United States population, however, they account for 45% (17,670) of HIV diagnoses in 2015. (U.S. Census Bureau, 2010).

African Americans carry the largest portion of HIV diagnoses in the United States. There are several reasons why this is happening. Treatment and prevention of HIV/AIDS in the United States has focused on individuals with a history of high-risk behavior such as unprotected sex and injection of drugs (McNair, Prather, 2004; Shrage, 2016). While these high-risk behaviors will put a young white adult at risk for HIV, young black adults without these behaviors are still at a higher than average risk for HIV mainly due to socioeconomic vulnerability such as poverty and spending time in a detention facility (McNair, Prather, 2004; Morin, 2015; Shrage, 2016;).

Compared to White American men, incarceration is six times as likely to happen in African American men. Incarceration rates and HIV/AIDS rates have quickly risen among African Americans during the past few decades (Morin, 2015; Rubenstein et al., 2016; Shrage, 2016). As a result of the rise in imprisonment among African American men, households, relationships and communities become destabilized (Morin, 2015; Rubenstein et al., 2016). One reason for increased risk for HIV are zero-tolerance policies in the United States that affect injection drug users, marijuana sellers and sex workers (Rubenstein et al., 2016; Shrage, 2016) These individuals will most likely end up in prison. While in jail or prison, HIV infection rates are 3-5 times higher than people not in jail/prison (Rubenstein et al., 2016; Shrage, 2016). If someone is on antiretrovirals for HIV before going to prison, their healthcare could be limited or even stopped. After their release, the inconstancy of antiretrovirals medication would have led to an uncontrolled viral load.

African American women represent less than 10% on the population in prison however, they account for over 50% of the heterosexual population living with HIV (Shrage, 2016).

According the CDC, about 87% of the African American women living with HIV were infected

through heterosexual sex with the remainder being infected through injected drug use or other pathways (Shrage, 2016; Morin, 2015). Due to the rise of African American men in prison, sexual partners among women may overlap. Also, African American women are more likely to have partners in the high-risk category of incarceration than any other group (Shrage, 2016). Many men who are released from prison do not consider themselves bisexual or gay although they had a sexual encounter with the same sex while in prison (Shrage, 2016). The stigma in the community about “low-down men” focuses on a person’s sexual history instead of his incarceration history which is influential to the rise of HIV/AIDS among African American women.

Stigma is a critical barrier to the prevention, care and treatment of HIV. Intersectional stigma is described by researchers as multiple interdependent social identities such as race/ethnicity, gender and age leading to different types of experiences of discrimination (Carmen et al., 2017; Morin, 2015; Sangaramoorthy, 2017). These experiences may negatively affect retention in care and antiretroviral (ART) adherence. Much of the research about stigma among people living with HIV (PLWH) focuses independently on gender, age, race and other demographic categories, however unique experiences and the impact of stigma on those with multiple socially stigmatized positions has been overlooked (Sangaramoorthy, 2017). In a study called HIV Stigma, Retention in Care, and ART Adherence, the authors examined three themes that prevent African American women from receiving HIV treatment. Within the realm of stigma, public silence, negative stereotypes, and avoidance/rejection were concerns among African American women. Despite medical advances and increased awareness of HIV, the African American community remains to stay silent about the subject (McNair, Prather, 2004; Sangaramoorthy, 2017). This public silence fosters negative stereotypes such as seeing PLWH as bad individuals. One participant mentioned “if you’re a Caucasian female, people are like, ‘I’m so sorry!’ But if you’re a Black female, they are like ‘drug user... prostitution...’” (Sangaramoorthy, 2017). The negative stereotypes then affect the participant’s perceptions of disclosure. Fear to disclose stems from experiences of rejection from loved ones. Participants explain experiences with loved

ones as having to clean the toilet every time they go to the bathroom or having to use plastic silverware whenever they ate (Sangaramoorthy, 2017).

Adherence among African American women pose many barriers such as lack of access, no coordination of care and routine financial hardship. A participant described her conversation with a representative at Maryland Medicaid as discomfoting (Sangaramoorthy, 2017). The participant called the representative of Maryland Medicaid and asked her if she could get a cab to take her to her appointment because she did not have money. The representative told her “you don’t need a cab because you can just take public transportation” (Sangaramoorthy, 2017). This caused the participant to not go to the doctor on a regular basis. Also, the additional cost of childcare prevented the women from regular HIV appointments as majority of them are the primary caretakers of their children or grandchildren (Morin, 2015; Sangaramoorthy, 2017). Many of the women explained, in order to stay in care they have to prioritize their healthcare cost even if it means borrowing money from family members, friends or reschedule appointments until they get money (Morin, 2015; Sangaramoorthy, 2017). HIV prevention among African American women is also a barrier of external stigma. Many African American women experience both accusatory feedback from partners and admission to infidelity when asking their partner to use a condom. If they are HIV positive, loved ones begin to treat them differently causing them to be unwilling to disclose their status (McNair, Prather, 2004; Morin, 2015).

### **Nutritional Impact on HIV**

A healthy diet includes a variety of nutritious foods and energy dense foods in moderation. However, nutrition for a person living with HIV, is very important for maintaining the immune system (Duggal et al., 2012; U.S. Department of Health and Human Services, 2018). Malnutrition and HIV is a dangerous cycle that can enter with poor nutrition status which is described as weight loss, muscle wasting and macronutrient or micronutrient deficiency (Duggal et al., 2012; Krause, 2016). Nutrition becomes a problem at the early stage of HIV and continues to worsen over time. It can

contribute to immune dysfunction and disease progression if it is not treated. There are several reasons why nutritional deficiencies are common. The first reason is nutrients burn faster. When the body is fighting an infection, the body needs more energy. The immune system is continuously fighting the HIV, even with antiretroviral medication being used (Masiá et al., 2016). Along with fighting HIV, the immune system is repairing damage caused by the virus and other possible infections. The next reason for nutrient deficiencies is poor nutrient absorption which is a result of intestinal infections or diarrhea (Masiá et al., 2016). Between 30– 50% of HIV patients in developed countries complain of diarrhea and malabsorption (Duggal et al., 2012). The gastrointestinal tract is the largest organ that is a part of the lymphatic system and is directly affected by HIV infection (Duggal et al., 2012). The lymphatic system is important in transporting some fats and works with the immune system to fight infections.

Malabsorption is a clinical manifestation of HIV enteropathy which is characterized by partial villous atrophy and mucosal inflammation (Corazza et al., 1997, Lauwers et al., 2010). The virus causes damage to the intestinal cells by causing the villi in to flatten and decreased absorption of D-xylose, the simplest form of sugar absorbed by the body (Duggal et al., 2012).

Malabsorption of lactose is also common in patients with HIV (Corazza et al., 1997, Lauwers et al., 2010). Lactose intolerance frequently occurs in advanced stages of HIV but, can be seen in early stages as well. Lactose intolerance is the inability to properly digest and absorb milk sugar, lactose, that results in gas or diarrhea. The severity of intolerance is highly variable with some people not able to tolerate small amounts of dairy products, while others would only react to large amounts.

This leads to poor absorption of carbohydrates and fat therefore leaving many people living with HIV with deficiencies in vitamin A, E, D, and K which are important for immune functioning (Duggal et al., 2012; Smith et al., 1992). Lastly, poor diets can lead to nutrient deficiencies. Many PLWH don't eat enough nutrient dense foods. This may be due to fatigue, appetite loss, changes in the senses of smell or taste, nausea, vomiting, infections or simply not knowing which foods will

support their support immune system (Masiá et al., 2016). Nutrients that are commonly deficient in people living with HIV are zinc, selenium, copper, B-6, and B-12 (all of which are important for an intact immune response; Masiá et al., 2016, Pereira et al., 2016). Glutathione, an important antioxidant that is produced in our bodies and naturally found in food, is also commonly deficient in people living with HIV (Duggal et al., 2012). As part of the body's responses to infection, it creates unstable molecules known as free radicals which are intended to destroy harmful bacteria or virus invading the immune system. When the bacteria or virus is destroyed, the free radicals are deactivated by antioxidants to prevent the further damage to the body. However, if glutathione or other antioxidants are depleted, the constant creation of free radicals will cause oxidative stress to the body (Duggal et al., 2012). Increased oxidative stress leads to apoptosis or death of T-cells and also indirectly stimulates HIV replication (Duggal et al., 2012; Reuter et al., 2010). It is crucial to keep optimal levels of antioxidants in the body to lessen the oxidative stress in the body. Malnutrition stimulates dysfunctions in the immune system and promotes increased vulnerability of the host to infections (Duggal et al., 2012).

Finally, HIV leads to an increased nutritional need. Due to malabsorption, poor food intake and viral replication, increased nutritional intake is critical (Krause, 2016). The cycle continues unless nutritional care and support breaks the cycle to boost the immune system and improve response to antiretroviral therapy (Krause, 2016; U.S. Department of Health and Human Services, 2018). HIV attacks the immune system but with daily HIV medication and a healthy diet, the immune system can continue to stay strong. Individuals living with HIV are at risk for increased nutrient needs, nutrient malabsorption, adverse drug interaction, frequent diarrhea, anorexia, nausea, and recurrent infections (Krause, 2016). Poor nutrition status can also slow healing process, possibly speed up the progression of HIV and worsening suppression (U.S. Department of Health and Human Services, 2018; Krause, 2016).

A healthy diet for someone living with HIV, is very similar to someone without the virus. However, to ensure the presence of all essential nutrients needed for those living with HIV, it is

important to make the most of what you eat. A healthy diet includes a variety of whole foods such as fruits, vegetables, grains, protein foods, and dairy along with plenty of water (U.S. Department of Health and Human Services, 2018; Krause, 2016). Choose starchy carbohydrates that are loaded with fiber. Eating a wide variety of vegetables and fruits guarantees a variety of nutrients and fiber for healthy immune functions. Protein is essential for a healthy body and a strong immune system (Pereira et al., 2016). There are many sources of protein which include beans, eggs, nuts, seeds, milk, yogurt, lean meat, poultry, fish, and cheese. The exact amount of protein a patient may need is based on individual needs such as weight, height, activity level, and disease state. Although there are many nutritious fat options, fat intake should be monitored and be kept at a moderately low level (Pereira et al., 2016). Research shows (Latshaw, 1991) excess fat can cause diarrhea secondary to malabsorption, it can act as an immunosuppressive, and could increase risk of cirrhosis for those also living with hepatitis C.

Food safety is very important for someone living with HIV because the immune system is weakened. Following food safety guidelines will reduce the risk of foodborne diseases such as listeria and E. coli, which will be more detrimental to someone with HIV because of their compromised immune system. A person living with HIV should be careful not to eat (1) raw or undercooked eggs, such as homemade mayonnaise or uncooked cookie dough; (2) unpasteurized milk, cheeses, and fruit juices; (3) raw or undercooked poultry, meat, and seafood, such as sushi (Krause, 2016; U.S. Department of Health and Human Services, 2018). Food safety guidelines include (1) washing hands, cooking utensils and surfaces often; (2) storing raw food below cooked food in the refrigerator; (3) thoroughly washing produce before eaten; (4) avoiding cross-contamination by not reusing utensils that were used on raw food and; (5) cooking to the appropriate temperatures (Krause, 2016; U.S. Department of Health and Human Services, 2018).

### **Social Services for Nutrition**

There are many services in the United States for food assistance for food insecure Americans such as Supplemental Nutrition Assistance Program (SNAP), Supplemental Nutrition Program for Women, Infants, and Children (WIC), Nutrition Services Incentive Program (NSIP), and Food Distribution Programs. These programs assist millions of low-income individuals in purchasing foods, nutrition information and provide some nutrition education classes (Green, 2016). Local food banks are another resource for obtaining nutritious food. Oklahoma has 358 food pantries and Stillwater has one food pantry called Our Daily Bread (Green, 2016). Our Daily Bread connects with local grocery stores such as Walmart, Aldi, and Sprouts for weekly donations. These stores provide a variety of fresh fruits and vegetables, meat, dairy, breads and canned goods. The federal nutrition programs along with local food banks are helping keep multiple families and individuals' food secure (Green, 2016).

### **Barriers to Accessing Services and Food Insecurity among People Living with HIV**

Food insecurity is defined as limited availability of safe, nutritionally adequate foods to meet dietary needs (Alexy et al., 2013; Kalichman et al., 2010; Spinelli et al., 2017). Food insecurity has a direct link to malnutrition, obesity, and metabolic syndrome, which all significantly predict mortality in people living with HIV (Kalichman et al., 2014). Food insecurity is associated with lower CD4 cell count in people living with HIV. In a study done in Atlanta, Georgia, the authors examined food insufficiency in relation to HIV-related health and treatment (Kalichman et al., 2010). There were 344 men and women included in the study. The participants completed measures of health, food security, and HIV disease progression and treatment. The authors hypothesized "experiencing insufficient food would predict HIV treatment status and HIV treatment adherence" (Kalichman et al., 2010). The results showed half of the participants were food insecure. The PLWH experiencing food insufficiency was associated with multiple

indicators of poor health, including lower CD4 cell counts, higher HIV viral loads, and poorer treatment adherence (Alexy et al., 2013; Kalichman et al., 2014). Nutrition intervention can independently improve a person's health and immune system with or without HIV. Food can slow muscle wasting and ensure proper absorption of medication. PLWH that are food insufficient are also more likely to get tested later rather than soon after contact. According to a study with 67% African American, food security among women living with HIV, food insecurity was associated with 2.08 times higher viral load (Spinelli et al., 2017).

Food insecurity affects about 14% of the United States population however, a quarter to half of the people living with HIV experience food insufficiency (Spinelli et al., 2017). Also, from the total adult population living food insecure, women experience more food insecurity than men (Spinelli et al., 2017). In the study, Food Insecurity is Associated with Poor HIV Outcomes Among Women in the United States, the authors aimed to examine the relationship between food insecurity and HIV clinical outcomes in a multi-site U.S. sample of women (Spinelli et al., 2017). Forty percent of the women in their sample experience some form of food insecurity (Spinelli et al., 2017). From the 40%, most of the women has higher viral load and lower CD4= cell count (Spinelli et al., 2017). The women in this study were predominantly (67%) African American.

Food insecurity is a known barrier to accessing and adhering to antiretroviral therapy (ART) (Kalichman et al., 2014). A study done in San Francisco found that one third of the homeless and marginally housed people living with HIV are severely food insecure. Among those taking ART, over half are food insecure (Kalichman et al., 2014). Food insecurity was associated with non-adherence or unsuppressed HIV (Kalichman et al., 2014). Essentially, food insecurity can lead to being underweight or overweight can contribute to increased mortality among people living with HIV. During an interview for the study, HIV Stigma, Retention in Care, and ART Adherence, a woman explained how she ran out of money to purchase food but, still took her pill. She became very sick and decided to hold off on her medication until she got money for food



(Sangaramoorthy et al., 2017). Women constantly are finding themselves choosing between eating or eating healthy foods or taking their medications.

Another barrier experienced by African American women living with HIV is inadequate transportation. Lack of transportation impacts attending doctor's appointment and disrupts medication adherence. Lack of transportation also prevents the ability to go to grocery stores or supermarkets especially if the individual lives in a food desert (Kalichman et al., 2014; Sangaramoorthy, 2017). Food deserts affect health outcomes in many populations. Food deserts are more predominant in African American communities that are impoverished. Young African American women who reported a lack of food at home, homelessness, and low perceived education/employment prospects had between 2.2-4.7 times higher chance of reporting high risk sexual behavior (Raiford et al., 2014). Antagonistic social conditions of poverty are among the most consistent predictors of disease progression and morbidity in people living with HIV (Kalichman et al., 2014; Raiford et al., 2014). Stable housing is also a prevalent barrier to accessing healthcare or education (Raiford et al., 2014). To address the effects of homelessness on the health of PLWH, the CDC and North Carolina's Department of Housing provided rental assistance to homeless and unstably housed persons living with HIV/AIDS. The assistance in housing was associated with positive outcomes for housing status, health care utilization, and mental and physical health in a randomized controlled trial of women (Raiford et al., 2014).

#### **Facilitators to Accessing Services for People Living With HIV (PLWH)**

There are programs in the United States that assist individuals living with HIV. In Tulsa Oklahoma, there is a facility called Tulsa Cares. The mission for Tulsa Cares is creating an environment where all people living with HIV have an opportunity to live a healthy life (Tulsa CARES, 2017). They provide five integrated services which include Care Coordination, Health Care Navigation, Healthcare Navigation, Food and Nutrition, and Mental Health Counseling (Tulsa CARES, 2017). Tulsa Cares offers a variety of fruits, vegetables and other nutritious food along with household supplies. They also offer weekly lunches for people living with HIV and

their guest, medical nutrition therapy, and nutrition education (Tulsa CARES, 2017). Tulsa Cares also, helps individuals with applying for assistance from the government. This resource is unique because it as an ecological approach to care.

## CHAPTER III

### METHODS

#### **Study Design**

This thesis utilized a qualitative research design to gain a holistic understanding of underlying reasons, motivations and, opinions related to the phenomenon of interest. The methodology I used is phenomenology which aims to understand the meaning and essence of the lived experiences of a person or group of people around a specific phenomenon (Moustakas, 1994). A phenomenologist strives to understand human behavior through the point of view of the participants. More specifically, this research will utilize transcendental phenomenology to seek a deeper understanding of African American women's personal encounters with HIV.

Transcendental means examining/exploring a certain phenomenon with an open mind and fresh eyes, resulting in new knowledge (Moustakas, 1994). This form of phenomenology requires the researcher to set aside prejudgments. The goal of this thesis study was to gain a deeper understanding of African American women's everyday experiences of HIV and their self-care. I recruited African American women living with HIV residing in Southern states for in-depth interviews. The data collected assessed the participants' feelings, perceptions and experiences of being an African American living with HIV. Specifically, the culture, discrimination, marginalization and place within these experiences was assessed to conceptualize participants' stories.

## **Participants and Recruitment**

The participant selection process was guided by the research question in mind (Flentroy, 2016; Merriam, 2009). Thus, purposeful sampling methods were utilized to find individuals with experiences of the phenomenon being studied (Flentroy, 2016; Merriam, 2009). The main goal of

this technique was to focus on specific characteristics of a population that are of interest, which provided an in-depth insight to the research question. In order to meet these goals, maximum variation sampling was utilized in order to capture a wide range of perspectives relating to the intersection of being an African American living with HIV and as an individual with nutritional implications (Merriam, 2009). The goal was to gain greater insights by looking at various angles (Flentroy, 2016; Merriam, 2009). Although the sample was comprised of individuals with homogeneous demographics, their lived experiences were unique and allowed for exploration of the variability. The initial phase of this study included identifying voluntary participants. During this phase, approximately ten to fifteen participants were recruited to participate in this study based on the eligibility criteria: 1) between 18-50 years of age; 2) identify as an African American woman; 3) report a positive HIV status; 4) reside a Southern state; and 5) report infection through heterosexual, intravenous drugs, or maternal transmission.

## **Procedures**

Before setting up interviews, I performed a process known as bracketing or epoché. This is a crucial foundation of transcendental phenomenology because the objective is to study only the experiences of the participants. Bracketing involved setting aside my own experiences, biases, and preconceived notions to make sure I was able to understand how living with HIV appears to the participant (Flentroy, 2016; Moustakas, 1994). As an African American woman, there are stereotypes I have heard and experienced about HIV and being Black. Therefore, it is

important that I unpack or peel away those preconceived notions so the participant's experiences will lead the research. Next, if the selected participants met the eligibility criteria and wished to continue with the study, an in-person or phone interview was scheduled at a location and time that was convenient for the participant. At the beginning of each interview, I explained the purpose of the study and left some time for questions. After, I gave the participant a consent form (Appendix 1) and read it over with them. The consent form included an overview of the interview process and an explanation on how their provided information would be used. Upon completion, they were given a basic demographic questionnaire that includes age, marital status, date and result of last HIV test, number of children, education, work status, sexual orientation, and health care benefits.

Since the study is exploring sensitive issues, the ethical obligation to maintain confidentiality of HIV-related information is very important to the success of this study. During the interview, I obtained personal experiences of being African American living with HIV. These experiences included stigma and family and friend interactions and interactions with medical professionals. Since this is a phenomenological study, the participants were asked to describe their thoughts, feelings, images, sensations, memories, along with a description of the situation in which the experience occurred (Moustakas, 1994). The questions prompted information about how they manage their HIV through food intake and medication without directing them to answer a certain way. The questions also prompted details about their HIV risk behavior such as unprotected sexual intercourse, substance use, and intravenous needle sharing.

The interview included in-depth, open-ended questions in order to triangulate the proximal and distal determinants impacting nutritional intake among this population of interest. The interviews were approximately 45 to 60 minutes in length and lead by the researcher. The interviews were audio recorded with the permission of the interviewees. Each participant was assigned a number, such as Participant 10. Each interview was transcribed and double-checked

for accuracy. At this point, audio files were deleted in order to maintain confidentiality. If within the interview the participant referred to their own name or the names of others, pseudonyms were used within the transcript to de-identify data.

## Data Analysis

### Interview Data Analysis

Qualitative research using transcendental phenomenological research design [process focusing one's lived experiences and meanings] were utilized for analysis of interview transcripts. I used transcendental phenomenology techniques to understand the experience of living with HIV as an African American women and the nutritional implications. A limitation of quantitative measures, such as the utilization of scales, tests, and questionnaires, is that they lack cultural sensitivity and conceptual understanding.

After the interviews were transcribed, I analyzed the data. The first step is horizontalization. This step included taking the significant statements from the transcriptions that describe elements of the participant's experience. The significant statements were sentences or quotes that described the participants experience as an African American living with HIV. Then the significant statements are placed into clusters of meanings. The themes emerged from the participant's experiences or feelings found in the clusters. The significant statements or clusters of meaning helped create a textural description. The textural description focused on what the experience is from the phenomenon being researched (Flentroy, 2016; Ping & Sumari, 2012). The significant statements were used to write a structural description. Structural description is a description of the context and setting that influences how the participants experienced the phenomenon. Next, the textural and structural description was used to create the essence of the experience (Ping & Sumari, 2012). The essence of the experience gave the readers a better understanding of what it would be like to experience being an African American woman living

with HIV and nutritional implications.

In a study entitled, *“God loves me no matter how I am”*: A phenomenological analysis of the religious and spiritual experiences of HIV-infected African-American women with depression, the authors utilized a transcendental phenomenological design (Himelhoch et al., 2016). The design was appropriate for this study to gain greater insight into the in-depth experiences of African American women’s religious practices and spirituality after an HIV diagnosis and living with depression (Himelhoch et al., 2016; Ping & Sumari, 2012). The transcendental phenomenological approach created themes into structural, which is the context of the experience, and textual, the participant experiences, descriptions. The authors used in-depth, semi-structured questions during the interviews. Unstructured probing and follow-up questions were used to provide a deeper understanding of their experiences. In another phenomenological study, the authors examined African American women’s lived experiences as college students at a predominantly White institution (Hannon et al., 2016). The authors relied on in-depth, unstructured interview tactics to collect their data because they wanted the participants to construct their own meaning of their experience. In both the studies, the authors performed bracketing to clarify researcher’s perspectives before conducting the interviews (Hannon et al., 2016; Himelhoch et al., 2016). During the analysis of both studies, authors started with reading the transcripts of each interview and flagging words and phrases that described the meaning of the lived experience and wrote summaries of each interview (Hannon et al., 2016; Himelhoch et al., 2016). Their next step was to create themes that emerged from the interviews that gave the readers a greater perspective of the experiences. Both these studies concluded with salient interpretations of the data collected. Similar to the present study, these studies focused on the participants lived experience in a certain phenomenon.

Previous researchers have utilized similar techniques to explore the lived experiences of African American women living with HIV/AIDS with social service agencies, healthcare agencies, and general societal settings. The group interviews were semi-structured so the participants had the opportunity and freedom to answer questions in their own way. The author also made sure not to predetermine categories for the responses until after the interviews were over. After the author transcribed and analyzed the interviews, twelve themes emerged (DeLoach, 2003). For each theme, there was a description of the meaning of the theme and complete quotes from the participants.

Phenomenology is very appropriate for the examination of understudied populations (DeLoach, 2003; Flentory, 2016; Himelhoch et al., 2016) It provides a deep meaning of lived experience through the participants thoughts, words and descriptions. As phenomenology is used by other studies to explore lived experiences of African American women living with HIV, the present study was successful by using this methodology.



## CHAPTER IV

### RESULTS

The objective of this phenomenological study is to understand the experiences of living with HIV as an African American woman and to examine the nutritional impact. For this study, in-depth interviews were conducted over the phone. Five main themes (see Table 1) emerged in the exploration of women's experiences of living with HIV: (1) women discussed processes of moving beyond the HIV diagnosis and moving towards acceptance (moving beyond and acceptance); (2) stigma occurring across different levels (experiencing stigma); (3) the importance of social support and relationships on coping; (4) discrimination from different groups; and (5) quality of healthcare. To place the themes within the context of the aforementioned identified issues, I organized the following subsections to highlight experiences and perceptions of the participants. Verbatim quotes from the data are presented to highlight and expound on connections. Participant numbers are used to maintain participant confidentiality.

#### **Sociodemographics of the Sample**

In the overall sample, participants' (n=7) mean age was 47.4 years (SD 12.15) and median yearly income before taxes was between \$20,000 - \$35,000. Most of the participants identified as African American and heterosexual (n=6); 14% of the participants do not have a high school diploma, less than 57% of the participants have a high school diploma or GED, and 29% have an associates or bachelor's degree; and two-thirds were receiving government assistance as their income, including disability, welfare or Medicaid. The participants are from Southern states:

Oklahoma, Texas and Georgia. Most of the women are unemployed (n=6) and 2 are looking for work.

#### **Moving Beyond and Acceptance Experience**

For each of the participants, the experience of learning about their HIV diagnosis was a pivotal point in their life. This experience was described in detail by all of the participants. Many recalled the exact date, time, and circumstances surrounding this experience. The participants' initial feelings were of shock, denial, anger, and depression. Although all the women did not follow the same linear pattern of the stages, they all had similar strengths that moved them towards acceptance of their diagnosis. I believe it is important to group these five stages into a category called Diagnosis Experience.

### **Shock**

The participants demonstrated a range of emotions during the initial shock phase. Some immediately "shut down" to their friends and family, including isolating themselves and losing their normality. Others experienced shock and denial simultaneously. As noted by Participant 4, "The first 2 years of being positive, I walked around like a zombie. I could not believe after all the reading I had done, that I was HIV positive, I couldn't believe it..." The participants still experienced shock, even though they engaged in condom-less sex, because they were all in perceived monogamous relationships with partners they trusted. Participant 4 explained reading a letter she received after her boyfriend's death which informed her of the real reason he was so sick: "We were together for 8 years, and he had HIV for 10 or so years. I remember sitting there looking at that sentence for about 3 hours, sitting in the same place." Since perceived safety and trust is a multidimensional construct that encompasses emotional, cognitive and behavioral dimensions, the shock of betrayal is amplified.

### **Denial**

Most of the participants experienced some form of denial upon first learning of their HIV diagnosis ranging from avoiding the diagnosis to projecting the diagnosis onto someone else. For example, Participant 1 detailed experience in which she seemed to jump straight to denial after

hearing her diagnosis saying, “I was very bull-headed and didn't want to accept it.” Evaluations of self-risk directly impact a participant’s level of denial. In particular, women highlight traditional at-risk populations and how their behaviors did not correspond. For example, Participant 2 said “I was not a drug user or a sex worker, I didn’t get any blood transfusion. It just was not adding up.” Such reflection led to questioning of initial HIV testing results and by ignoring the diagnosis: “My doctor urged me to begin the medication right away. I just didn't believe the test. So, I was not taking the medication for about 10 months after I got the diagnosis.... I felt fine. I didn't feel sick” (Participant 1). Given that many of these women were asymptomatic and in overall good health, HIV was not brought to the forefront of their lives and often women forgot about their diagnosis, “but after a while, that is simply impossible to do” (Participant 1).

### **Anger**

Given that an HIV diagnosis can be a traumatic experience, some participants expressed feeling angry with themselves and also with their partner. These feelings manifested into physical bodily reactions and all their expressions. In particular, Participant 2 described her initial reaction as feeling a knot in her throat, numbness throughout her body, and leading to the evaluation of her relationship partner: “I was mad and angry. And now I am having a baby by a man who took my life.” She felt betrayed by the man she had been with for many years and still “to this day he has not admitted he is the one who gave it to me”. This anger was often internalized by these women, including bearing blame and guilt. This process is best highlighted by Participant 6 who explained, “I should have known better. I was so sick with myself.” Women also reflected on experiences in their lives which should have informed their own potential risk-taking behaviors. This often was observed within their immediate familial and social groups: “My mother also died while I was in prison from AIDS. She was infected by her spouse who went to prison for 2 years” (Participant 2).

## **Depression**

All participants identified some level of perceived depression associated with their lives as a person living with HIV. This is the only stage in the diagnosis experience that was initiated by each participant without my use of probing questions. Depression was something each of the participants went through during the initial diagnosis, but it is something a few still deal with continually after 10+ years of living with HIV: “I went through depression, anxiety ummm... I wanted to give up, I didn't want to live with it. I left like that for...a couple of years” (Participant 2). Some women expressed feelings of despair and self-pity: “at first...when I first found out about it, I lost a whole year by going through depression. Saying stuff like, ‘why me?’, why it had to be me?” (Participant 5). As highlighted by Participant 4, worthlessness was also a common feeling among the women after being diagnosed with HIV: “Because I lost myself so deeply, I began to let anyone talk to me or treat me anyway.” A couple women described depression as an ongoing and fluid feeling which is usually triggered by the actions of others: “When I am constantly being turned away from a job, it makes me what to say fuck it, and I just lay in bed for days” (Participant 7).

## **Acceptance**

All the women have accepted their diagnosis and described it as a transitional time marker in their lives. Many women denoted that something within them changed. For all the women, the diagnosis served as a wake-up call and a different beginning: “I realize, I need to go to the doctor if I am going to live. I have HIV, HIV doesn't have me! I won't stop being me” (Participant 1). Although the environment has a tremendous impact on life outcomes, women noted that it did not mean they had to continue on a path in which HIV defined their existence. As noted by Participant 2, HIV became part of her experience: “Unfortunately, things happen. Nurture vs. Nature. I was an inmate... then became HIV positive dealing with another felon, and I am still living my life.” A few women expressed losing themselves and how acceptance helped them gain strength: “I lost myself and my strength and had to find it again...So, I decided to get busy living

instead of dying. So, here I am today!” (Participant 5). For others, acceptance was linked with disease progression and the need to survive. This was reflected in the experience of Participant 6 who was diagnosed at a later stage when symptoms became apparent: “I didn't find out I had HIV until I was hospitalized. I was just getting so sick and nothing was working. The doctor told me I had HIV and I had to make a decision right there, am I going to live or die?” Women discussed how there were two paths that could be taken at this point. Someone could go on ignoring what is happening with their body and eventually die or acknowledge their new reality and thrive.

### **A New Me: Empowerment of Self and Others**

Most of the women expressed a change for the better and that their diagnosis made them look at everyday as an opportunity to learn and give back to other women. Such changed allowed women to explore areas that were important to them and to also evaluate where to put their time: “I like to teach others and create a safe stay for Black people living with HIV. I think it is so important to have a support system that understands what you are going through. I am much more open to learning and talking about the importance of getting tested and not being scared” (Participant 1). Instead of looking at their diagnosis as a burden, many women look at it as a tool for teaching:

Now, that I know about it, I am teaching about it to anyone that wants to listen. I am a part of a group called RISE, Recovering Intervention, Support and Education. In this group I try and help get people on track. Telling them that there are more ways than the way you are going. Cause there's no shame in mine. I'm in it to change the game. I'm tryna reach one teach one. That's what I am trying to do! (Participant 5)

For others, having discussions related to their diagnosis provided to new opportunities to not only give back to the community but also was a self-empowering activity:

I gained the power to speak openly about my life and I gained the courage to run to be on the board at the clinic. So, I have a lot going on. People are like “wow”, but God gives me strength to attend everything, so I am blessed. (Participant 5)

As I spoke with Participant 6 about HIV prevention within the Black community, there was agreement that a priority is the need to reach the younger population if anything is going to

change: “I have a passion for young teenagers. I am more into helping and teaching them to do better.” This passion is played out in the actions of Participant 6 who also houses at risk young adults in her home and helps them with finding jobs and receiving their GED: “I teach these teens about staying out of trouble and keeping themselves protected when having sex. Keep themselves protected at all times, no matter what somebody tell you” (Participant 6). Through all the pain and feelings of betrayal, many women say the diagnosis has made them a better version of themselves: “The diagnosis... has made me a better person to be honest. It has made me open my eyes and look at a lot of things differently” (Participant 6). Most of the women have learned more about themselves and in return, it allows them to help someone else. Many of the women talked about the role of the Black mother or caregiver in the community and how the role at time compromises self. Now, they tell every woman they come in contact with that it is “okay to put yourself first” (Participant 1, 3).

### **Experiencing Stigma**

From a historical context, reports of HIV/AIDS epidemic in the United States primarily seemed to greatly affect gay men and intravenous users. This narrative emphasized individual behavior and stigmatized identities. HIV was not only connected to death but also sexuality, promiscuity, and illegal drug use. As persons living with HIV, all the women reported experiencing some level of stigma from friends, family, and/or health care professionals. It became relevant to flush out the role of stigma because the women expressed many different types of stigma and it was a recurring experience among all the women.

### **Internalized Stigma**

Most of the women admitted their preconceived beliefs that most of the community has towards people living with HIV before their HIV diagnosis: “Before my diagnosis, I always thought you had to be doing drugs or be a prostitute to get HIV. So, I’m sure that’s why many people, like myself, try to avoid dealing with the HIV at first” (Participant 1). Although all of the women expressed acceptance of their new reality, many women were still battling with how they

contracted HIV. As highlighted by Participant 2, many women associated risk with certain behaviors that did not align with their own experiences: “Like, sometimes I am still not okay with me having HIV. I was not a prostitute or a drug addict.” A couple of the women talked about when they were going to tell their youngest grandchildren about their status: “I don't want to tell my grandson yet. I feel like he is too young to understand. I don't want him to have any negative perception of his grandma. I don't want him to think I'm dying either” (Participant 4). One of the participants, who was born with HIV, talked about reasons why Black women get HIV saying, “I feel like Black women have more sex” (Participant 3). This narrative furthers the stigma among Black women.

### **Stigma from health care providers**

For the most part, the participants indicated that they have positive relationships with their health care providers they are currently with: “I have an excellent relationship with my doctor. When she left the practice that she was in, I followed her. Dr. T is very passionate about HIV in the African American community. She has done presentations as well over health and HIV.” (Participant 4) However, it took them awhile before finding the right provider that understands their needs and experience. Participant 1 noted how some providers were not initially inclusive of HIV-positive clients: “The doctor I had when I first found out, my doctor was not...sensitive to my feelings and what I was going through.” About half of the participants express overall contentment with their healthcare providers, but finds themselves holding back when talking about certain issues:

I usually don't bring up a certain topic because I feel like I am being judged. Well just talking about the medication that would work for me. For example: smoking marijuana. I smoke marijuana to get the “munchies” so I can eat. I lose my appetite a lot and that's how you get so little when you have HIV. But I smoke marijuana a lot to keep my appetite going. They look at me like I am terrible person for smoking marijuana but they also need me to eat! ... they make me feel like I see dead people. Like I'm not talking real. (Participant 4)

Although most of the women indicated that their healthcare care providers have done well attending to their needs, the process it took them to finding their current provider was extensive but necessary in order to ensure their health:

I have a wonderful relationship with my doctor. She is like a best friend too because she is very honest and open and I really like her because she keep it real. I was with another doctor before, but I never felt comfortable with them. It's like, they never took the time to get to know me. It's like they were just concerned with how I got it and how to treat the HIV. (Participant 6)

### **Stigma from family and friends**

Many of the participants mentioned in detail various situations they sensed stigma from relatives and friends. The stigma among family and friends seemed to take more of a toll on the women than stigma among healthcare providers: “Soon as you say something about your status, people are like... trying to put themselves in the equation... like asking themselves can I still hug her.” (Participant 7) Since the Black community can be small and close knit, it is difficult to avoid stigmatizing behaviors from others. This need for community but also the relative smallness of communities was particularly salient for Participant 6 who stated: “The city is big but, it is still a small town. I sometimes get weird stares and people saying little things about me and it is getting back to me. I am just trying to stop the stigma .... Because it's not contagious, we don't got it, it got us.” Many women touched on the lack of education on sexual health which perpetuates the stigma among their friends and family: “My so-called friends were scared of something that they didn't know about. Which made them scared of me. And they are more danger to me.” (Participant 5) Similarly, participant 4 said, “people are scared of people with HIV and I am more scared of them than they are of me.” The perpetuation of stigma was an opportunity to also educate community members. In particular, to disentangle the perception that HIV infection only occurs among individuals who deviate from socially prescribed norms. For example, Participant 1 works with minorities living with HIV and she tries to remind them “not everyone who is infected has gotten it from doing something dirty or illegal.” She also explains how stigma from family



can make a relationship “turn into an acquaintance real quick”. About half of the women talked about the differences in stigma based on male and females. Women are already placed into certain categories based on how they choose to express their sexuality. Therefore, an HIV diagnosis will only further the assumptions of a women’s sexuality and sexual behaviors: “I feel like women hold so much more shame because they are constantly up against people questioning their sexuality or something” (Participant 5). Participant 4 said stigmatizing comments such as “oh you slept around; you were easy” make it difficult for Black women to have a relationship with anyone outside of people familiar with the disease. This implicit and explicit shame causes many women to avoid friendships and romantic relationships: “I keep to myself. Besides when I go to my groups and the two ladies that are in my group... I am mainly a self-person. I have always been an introvert but, probably more so because I can't deal with people ignorance” (Participant 6). These quotes give insight into the difficulty women have with keeping relationships with people before their diagnosis and dating. Although many of the stereotypes have been debunked about HIV, many people are scared of becoming infected by showing affections such as hugging or kissing.

### **Social Support and Relationships**

HIV stigma and discrimination have a range of consequence such as emotional, physical, and financial. Stigma and HIV-related stigma can have direct effect on the health and mortality of people living with HIV. Women who do not have positive framing institutions or social support are more likely to have higher perceived stigma and negative self-image. Social networks are important source of empowerment which leads to a reduction in HIV-related stigma and its distal effects such as depression and anxiety. All of the women in this study received support from a variety of sources as they moved from the traumatic discovery of their diagnosis to acceptance of the diagnosis and themselves. The subcategories identified were family and friends, healthcare providers, and support groups.

### **Friends and Family**

All of the participants talked about certain people in their lives that have encouraged them throughout their process and still with them today. Participant 1 quickly claimed her family as her number one support system: “My sons and my brother are my biggest supporters. And I am so grateful for it. I know many people become distant with their family after their diagnosis. They didn't believe me at first but they never judged me; they just offered their support” (Participant 1). Participant 5 also shares the same sentiments as Participant 1, in that they both have strong supportive familial systems: “My whole family, my whole entourage of friends and family.

Everyone I am around has been very supportive of me...They are proud of me because I am HIV positive and I have been living with it 15 years and I am not afraid to voice my opinion and also try stop the stigma around me” (Participant 5). The family support is something many women living with HIV do not have after their diagnosis as stated by all of the women. Most of the women who have familial support also have a family history of HIV: “No, I am not the only person in my family that is positive but, the only one that is vocal about my situation. They are on medication so, that's all that matters right now” (Participant 5). Participant 6 talks about her “unconventional” support from her young children and underserved teenagers in the neighborhood: “I have a passion for young teenagers. I am more into helping and teaching them to do better. They honestly are my one of my biggest supporters” (Participant 6). While others, like Participant 7, attributes her survival to her husband:

One of the reasons that I've been able to survive this long is because of my husband...Without my husband... even though I have a degree, I would be poor. I know it is difficult for many people to have meaningful relationships with someone who is knowledgeable and non-judgemental. So, I know I am blessed!

As within-group stigma impacts various communities that are impacted by HIV/AIDS, a couple women mentioned the LGBT community being more supportive than the Black community:

“There are a lot a gay men that are more supportive that I have found other than my family.”

(Participant 1) The LGBT community for these women are more accepting and get to know the person rather than further stigmatize the women: “The biggest supportive community is the LGBTQ community. They just are so welcoming and true to who they are. I respect transgender people because, it is what it is. They are not on the down low or it’s not secretive.” (Participant 2)

### **Healthcare Providers**

All of the participants placed an emphasis on their relationship with and support from their healthcare provider regardless if their experiences were positive or negative. Most of the women have positive relationships with their healthcare provider, however it took time to find the doctor who understood their needs:

Oh, my goodness. I had one doctor...I didn't like that doctor because he didn't care about...my life. Just wanted to make sure I was taking the medication. Then I went to a [another clinic] and their care is exceptional! I love it. They take time... Everything. They are very personal, upbeat, calming. If I am not feeling well she will send me a taxi. (Participant 2)

Many of the women mentioned their diagnosis was accompanied with depression and anxiety therefore, it was important to have a provider who cares about the person living with HIV rather than just the HIV. As noted by Participant 2:

There are other illnesses that come with HIV such as my depression and anxiety which were the two major things that I was dealing with... with my HIV when I was first diagnosed. My first doctor didn't help or provide treatment for that. My current clinic has therapist, a food pantry, social groups and a medical doctor.

These institutions provide more than just medical advice, they supply an alternative means of support when the preexisting social group has a limited understanding of HIV/AIDS:

Dr. T is very passionate about HIV in the African American community. She has done presentations over health and HIV as well. She helps...I guess normalize my life. She cares about how I feel and what’s going on in my life HIV-related or not. (Participant 4).

Once the women's needs are met and the doctor has made a conscious effort to establish a relationship, the women began to create positive coping mechanisms. This led to deeper patient-provider relationships and mentorship opportunities for those looking for new opportunities to give back:

I have a wonderful relationship with my doctor. She is like a best friend too because she is very honest and open and I really like her because she keep it real. She is part of the reason I got involved in helping women with HIV. (Participant 6)

I love working at [HIV community-based organization]. It really gives me purpose and feeling of wholeness. After creating a relationship with my doctor, I began to seek out organizations that help Black people with HIV. Now, I like to teach others and create a safe space for Black people living with HIV. (Participant 1)

### **Support groups**

HIV-focused support groups and services served as critical coping strategy for all the women in this study. Through regular support group meetings, information sessions, and involvement in the community, the respondents were able to find a sense of balance, acknowledge past mistakes, and continuing to learn how live a healthier life whether that is safer sex, eating healthy, or taking mental breaks throughout the week. One of the women made a conscious effort to surround herself with positive thinking women: "I am in a sorority of group for women living with HIV. It is just a great thing. It the best thing that ever happen to me in my life. They are always positive and with HIV, you need people who are uplifting" (Participant 5). All of the participants expressed feelings of isolation after their HIV diagnosis and feeling left out of their preexisting circles. After finding a group or institution that accepts them without preconceived notions, they went from seeing HIV as a death sentence to thriving with HIV: "when I found out I was HIV positive, I thought I was in the world by myself, but when I found out all these people going through the same thing I am going through it made it easier for me" (Participant 5). Support groups have empowered many of the women in this study to help others not just living with HIV but dealing with addiction: "I am a part of a group called

RISE, Recovering Intervention, Support and Education. In this group I try and help get people on track. Telling them that there are more ways than the way you are going” (Participant 5). The tools of substance abuse treatment reflect HIV management strategies and practices. As explained by Participant 5, “people trying to recover from addictions need to avoid people, places, and things that threaten their progress” which is similar to strategies of HIV management. The number one attribute of social support networks is safety. In order for the women to feel safe in the social environment, they needed to hear and see consistency support from the framing institution. Since the illness is highly stigmatized with few coping resources, the women felt it was important to reach out to others outside their familial and medical support networks to help them blend the illness into their everyday lives:

After the diagnosis, putting my trust in people.... I guess seemed daunting. Because you did not know if they would really care about you or just sit and look all sad for you. Thankfully, my support group treats me like a normal woman. We also look out for each other outside the group. I’ve made long-lasting friendships. (Participant 6) I am involved in one group which is a mental health group. This group is like a social class where they talk about ways to care for your mental health. Sometimes we paint, do yoga and others things. They class is for more than just people living with HIV too... everyone is accepting of one another.” (Participant 3)

### **Discrimination**

Discrimination is a social process that results from social inequalities inherent in people’s lives. General discrimination and HIV related discrimination may affect the health of a woman living with HIV, but also how the participant copes with and internalizes this discrimination. When discussing socioeconomic status as a predictor of health, it is equally important to note the direct correlation of discrimination on health status. For example, racial residential segregation leads to inequitable service provision which describes the area all of the women in this study reside in. The sub-themes that emerged from the discrimination theme are family/friends, workplace, and

healthcare setting.

### **Family/friends**

Living with HIV with persistent discrimination can make it difficult to move forward after an HIV diagnosis. As stated in interviews, “family can either help you or break you”, therefore discrimination from family can have a tremendous effect on disease progression (Participant 4). This played out specifically within family social events where in participants were singled out due to their diagnosis: “Even family stigmatize you because they don't understand. They don't want you to eat off their plate. You have your own special plates, spoons, forks, glass, things like that. I mean really... that would push anyone over the edge” (Participant 4). One participant recalled wanting to hit her aunt for saying hurt things to her at a family reunion in front of the entire family: “My aunt said, that's what you get for sleeping me every Tom, Nick, and Harry. My own aunt. It was humiliating. Even though I know how I got HIV, they will almost have you believe their shit” (Participant 4). Some of women expressed how their family impacted their self-esteem directly as well as indirectly: “Before I contracted HIV, my mom would talk about one of her cousins with HIV and would talk about cleaning the toilet with bleach after she left the house... So, it took me a while to tell her about my status because... I just knew she would start treating me like that” (Participant 6).

### **Workplace**

Under the Americans with Disabilities Act (ADA), HIV & AIDS qualifies as a "disability." This is supposed to protect people living with HIV against discrimination by employers. There is no obligation on employees to tell their employers about their status except for certain professions in surgery or healthcare workers working with blood. However, if the person experiences symptoms from the HIV it may be helpful to disclose their status as the person may require time off due to illness. One of the participants recounted when she found out she was HIV positive, she disclosed to her friend which also happens to be her boss.

The doctor called me and asked if I could come into the office so, I went before work. They told me I was HIV-positive, and I was frozen. I decided to go ahead and go to work anyway.

My friend, which was my boss, could tell something was wrong with me because I am usually so much cheerier. She was telling me, you know you can tell me anything. So, I just spilled out how I felt, and I told her about my diagnosis. I really was vulnerable to this woman. Literally the next day, I was fired... me and my partner. He worked in a different area but, somehow, he was also fired at the same time. (Participant 2)

A couple of the women smoke marijuana so they are able to have an appetite so they are able to eat on a regular basis: "I have been smoking marijuana for 25 years, and it helps with appetite, it helps with the medication, if I was to not smoke marijuana, my day would look like... in the bed all day with my head in the trash can from throwing up." (Participant 7) Unfortunately, many of the jobs Participant 7 wanted require drug tests: "I went on a job interview and it was with a temp company, and the temp company said, if one of the companies wants you to take a drug test, would you be able to? So, I lied and said yes. When I go on interviews, I tell them about my condition and why I needed to smoke marijuana and of course... I don't get the job." (Participant 7) This participant is also aware of the disparities in securing livable wage job as an African American woman:

I am already a Black, dark skinned woman with dreads. I already have some much up against even though I have my bachelor's degree. I dress nice, my hair is always put together... I know what they are thinking when they look at me and then I tell them about the marijuana and HIV... it's depressing. (Participant 7)

### **Healthcare Setting**

Legally and ethically, healthcare professionals cannot refuse treatment to patients based on race, sex, sexuality or religion. However, many healthcare professionals are not aware of their hidden bias which was experience by these participants. Hidden bias affects attitudes and beliefs that can ultimately lead to stigma and discrimination. Hidden bias stems from lack of knowledge and

irrational fear. The women in this study described the discrimination in the healthcare professionals in an inconspicuous way to a very obvious manner: “I went to the doctor and the nurse came in to take my blood pressure. She put on gloves before taking it. She wasn’t even touching skin or giving shots!” (Participant 4). As healthcare professional, it is imperative to provide adequate and timely care to patients, especially those living with HIV. However, one of the participants discussed experiencing differential treatment from one of her previous doctors:

I felt like one of the doctors I had was racist. I was going through something, and I wasn't getting the type of response that I needed. It was taking her months to get back to me. Somehow, it blew up out of proportion, and I felt she was very nasty. When I asked for another doctor, they made me go back and see her, and it wasn't a good visit. She sent me a letter saying she wasn't going to be my doctor anymore based on my attitude and sent her one back... “I tried to get rid of you anyway.” She just blamed me for the entire situation. (Participant 7)

For Participant 7, their experiences surrounded preconceived notions by physicians that she may abuse controlled prescription medicines:

I was going through some muscle spasms and she was trying to make it seem like I was contacting her to get some narcotics. First of all bitch... Oops excuse (laughing)... I don't know the difference between narcotics and pain pills. All I know is that I was in pain. And when you're in pain, you're not going to have a good doctor's visit if they are asking you smart ass questions... you're just not going to have a good doctor's visit.

Instead of her physician asking her questions about the pain, she asked her questions to validate if she was actually having pain. These experiences within the healthcare setting were noted by participants to contribute to accessing HIV prevention, care and treatment services and adopting key preventive behaviors among patients.

### **Quality of Healthcare**

Patient quality care begins with the health workforce. Therefore, it is important to care for the whole person instead of treating the numbers or the lab values. Throughout this research, the sub-themes that emerged from Quality of Healthcare are cultural competency, mental healthcare,



nutrition education along with medication. Many of the conversations about the sub-themes were not probed and were very important to the women in this group.

### **Cultural Competency**

Effectively treating patients living with HIV requires more than just asking about symptoms and checking viral load. It demands an understanding of the experiences, circumstances and history. One of the women in this study discussed her experience with a doctor who did not take the time to get to know her or take interest in how she is doing:

The first doctor I was going to only asked about my symptoms from the medication, changed the dosage or something and then the appointment was over. It always seemed like he was just trying to get in and out. It takes me 30 minutes to an hour to get to the appointments and he saw me for 10 minutes. I just stopped going.

(Participant 3)

Many of the participants do not own a car which makes their commute to their doctor's appointment much more extensive. One of the participants recalls a time her doctor asked if she could move her appointment to a different day without considering her time and schedule:

So, I have to take two buses to get to my doctor's appointment and it makes it more difficult to do so, when the weather is all over the place. One day, my doctor wanted to move my appointments to Thursdays from Wednesdays. He didn't ask if that would work for me. He didn't know that I took the bus or that the buses schedule changes a little on Thursdays. (Participant 5)

Many participants currently have very culturally competent healthcare providers. One participant expressed gratefulness about her current healthcare provider. "I go to [HIV organization] and their care is exceptional! I love it. They take time.... Everything. They are very personal, upbeat, calming. If I am not feeling well, she will send me a taxi to make sure I make my doctor's appointment" (Participant 2).

The women who discussed positive experiences with their providers take time to talk about life and make sure their needs are met. This allows the women to be more transparent when talking about any issues they are experiencing with the HIV.

### **Mental Health**

People living with HIV are at higher risk for mental health disorders. An HIV diagnosis is life changing and many people experience depression and anxiety. Problems such as having trouble getting needed services, experiencing a loss of social support, experiencing a loss of employment, and facing the stigma and discrimination associated with HIV/AIDS can contribute to stress, depression and anxiety. It is important for healthcare providers to recognize mental health as a priority with patients living with HIV. Adding a HIV diagnosis on top of an already stigmatized phenomenon within that Black community makes it undeniably challenging for Black women living with HIV to seek and receive mental health support. As previously stated, most of the women in this research discussed their mental state after their diagnosis. The women thought some type of therapy is important no matter if it is from a therapist or a mental health support group: “I believe in therapy. When I was first diagnosed, I didn’t even consider therapy an option because I did really hear about it until after the diagnosed” (Participant 2). Mental health support has shown to increase retention in care however, when someone has a negative experience with therapy or a mental health provider, the likelihood of returning or seeking mental health care is slim:

At the ID clinic at [HIV clinic], they have a therapist for their patients. So, I was seeing that therapist and she knew I smoked marijuana and she knew why. So, during the summertime, my grandson was coming to stay with me, and I was telling her how excited I was about it. This fraud had the nerve to say to me... “you know if you smoke around your grandson, I will have to report you to social services.” I was livid. After all this time of getting to know me, and knowing the reason I smoke, you still treat me like I’m some addict. (Participant 7) Situations like this prevent many marginalized communities from seeking help and further influence negative coping behaviors.

### **Lack of Nutrition Information**

The role of nutrition in HIV/AIDS is largely overlooked. Nutrition plays a key role in health for all individuals. Eating nutritious food and the right amount of food is a critical component of

comprehensive care and treatment for people living with HIV and AIDS. A large portion of the immune system resides in the gastrointestinal tract. It serves as a barrier between pathogens in the external environment and the body's internal environment. However, the HIV virus compromises that barrier and increases the risk for contracting opportunistic pathogens. While highly active antiretroviral therapy (HAART) has reduced the impact of some gastrointestinal tract conditions, the women in this research experienced conditions such as diarrhea, lactose intolerance, celiac disease, osteonecrosis, metallic taste and lack of appetite. These conditions can alter food intake and increase disease progression. When the body is constantly fighting a virus, the energy needs will increase but, if someone is experiencing any of the conditions mentioned above the patient's food intake decreases. Most of the patients in this study said their healthcare provider has never talked to them about nutrition or referred them to a Registered Dietitian for nutrition education: "I have diarrhea occasionally... it happens about twice or three times a month....No, I have never heard any nutritional advice from my doctor. I have to take it upon myself to get the nutrition information" (Participant 2). Most of the women in this study experience occasional diarrhea.

Participant 4 was diagnosed with celiac disease about 18 years after her HIV diagnosis. She noticed she was experiencing gastrointestinal pain and have diarrhea on a regular basis: "I was diagnosed with celiac disease about 5 years ago. They first said it was Irritable Bowel Syndrome. The doctor told me to avoid gluten and... that's about it." (Participant 4) Celiac disease is caused by an immune reaction to gluten protein. Over a period of time, the intestinal lining becomes damaged resulting in malabsorption. The damage often causes diarrhea, fatigue, weight loss, bloating and anemia (Murray, n.d.). The only treatment is a gluten-free diet. Without proper nutrition education, the patient might not receive essential vitamins and minerals or find herself taking-in food that has gluten in it (Murray, n.d.). One of the participants was born with HIV and has been living with HIV for 27 years. She was diagnosed with osteonecrosis which resulted in a hip replacement: "I had a hip replacement in April. The bone in my hip did have any blood circulation so it was basically dead. So they needed to replace it... They did not

tell me why it [no blood flow] was happening.” (Participant 3) The participant was not advised on her diet although diet could help preserve bone mass. Two of the women in this study were diagnosed with lactose intolerance after their HIV diagnosis. . The HIV virus can damage the lining of the small intestine causing a deficiency in lactase, an enzyme used to break down lactose. As a result, the patient will have diarrhea, gas and bloating after eating or drinking dairy products: “I began to notice I would eat and get terrible pain in my stomach and be on the toilet for a while! I went to the doctor and I was diagnosed with lactose intolerance. She told me to stop eating dairy products.” Lactose intolerance can be severe or mild depending on the person, but it is important that the patient is still taking-in foods that provide calcium, vitamin D and phosphorus (Duggal, 2012). Lastly, all of the women, talked about their appetite changing after the diagnosis. HIV or the HIV medication can cause loss of appetite and change in taste, as indicated by Participant 4 “...I don't know what it is about meat...They just have a strange flavor. I can't put my finger on the taste.” Other women describe meat as having a metallic taste or making them feel sick, therefore, most of them will avoid eating meat.

## CHAPTER V

### DISCUSSION

Though HIV from the start of the epidemic disproportionately impacted African Americans, many did not realize they were at risk, fueling infection in these communities. HIV infection has declined among the United States population, but it continues to affect African Americans women. African American women have different risk factors that increase their incidence of HIV infection. A large body of research identifies risk factors such as injection drug use, crack cocaine use, exchanging sex for money or drugs, having concurrent sexual relationships, and not communicating sensitive issues with sex partners. However, for women within this study, risk of HIV infection was not solely a product of individual risky behavior. The goal of this study was to gain insight into the lives of African American women living with HIV. It was crucial to understand the disparity among African American women, access to health and social resources, and how the disease can be life altering for an African American woman

The findings in this research revealed five main themes and 14 subthemes. From these themes and subthemes evolved interpretative statements that contextualized the experience of being an African American woman living with HIV. The meaning of living with HIV for this group of African American women was a dynamic pattern of resilience, self-transcending adversity, using knowledge as empowerment, and teaching others while caring for themselves. Their experiences demonstrated their ability strive for happiness and rise above feelings of despair and loss.

## **Relationship of the Findings to the Extant Literature**

Overall, the current findings add to growing literature within this population. Stigma on different levels continues to be a recurrent theme in HIV research among African American women. In a phenomenological study approach by Amutah (2012), she identifies internal stigma as the biggest predictor of anxiety and depression among her participants. Similarly, in the present study, internal stigma caused the women great distressed. Positive framing institutions that facilitate interactions, create shared knowledge, introduce women to social ties which connect them to a diverse array of services, and actively de-stigmatize HIV reduce internalized stigma (Watkins-Hayes et al., 2012). Similar to other studies looking at African American women living with HIV, the women in this study revealed their healthcare providers as initiators of their pivotal moment in their lives. This finding emphasizes the need for cultural competency and education among healthcare professionals.

Notions of discrimination emerged as a primary concern for women within this study. Unlike other studies, this sample had higher education attainment levels and yet experienced increased levels of discrimination. Similarly, African American women in other studies express anger, embarrassment, and hurt when dealing with thought to be close friends and family who are ignorant about HIV transmission (Amutah, 2012; Smith et al., 2015; Watkins-Hayes et al., 2012). The ignorance from family and friends was attached to lack of sexual health knowledge and stigma related to sex and drugs, which are taboo in the Black community (Amutah, 2012; Smith et al., 2015; Watkins-Hayes et al., 2012; Wingood et al., 2007).

There is a continued need for research, which evaluates the role of incarceration on HIV health outcomes among African American women. Shrage (2016) notes that incarceration rates for the Black community are on average six times that of their White counterparts. This disparity is in great part due

to zero tolerance policies in the U.S. For example, many injection drug users often ended up in prison for possession of controlled substances and paraphernalia—instead of putting resources into communities to address addiction. At the community level, policies continue to hinder harm-reduction programs such as provision of condoms or clean needles although prisoners engage in consensual sex, drug use, and tattooing while in detention (Shrage, 2016). For those who are incarcerated and living with HIV, this can interrupt their HIV care and may lead to increase in viral load. Whereas for others, participants felt there should be mandatory HIV testing before they are released back into Black communities.

A novel finding within this study was the desire to teach others and how these activities self-empowered the participants. Most often empowerment is built through enhancing social support (Sangaramoorthy, 2017; Smith et al., 2014; Watkins-Hayes et al, 2012). Although feeling empowered through support groups leads to making healthy decisions and positive behavior outcomes, empowerment through teaching can produce the same results along with reducing stigma and increasing knowledge among those in their community. The literature describes expert patients as individuals who are able to effectively self-manage their long-term condition (Kielmann & Cataldo, 2010). Within the current study, women began to seek knowledge about their condition and the role of stigma in their community. They were not satisfied with keeping this important knowledge to themselves and wanted to educate others as a method to decrease HIV transmission.

There remains a gap in the literature related to nutritional health outcomes among African American women living with HIV, specifically in the current era of antiretroviral therapies. Nutrition can have a positive impact on the immune system or a negative impact—thus it is a vital component for individuals living with chronic conditions. People living with HIV have higher energy needs but have limited intake (Kalichman et al., 2010). Although there is a vast amount of

literature showing gastrointestinal function and nutritional status being affected by HIV, it is still overlooked by health professionals (Kalichman et al., 2010; Mahan, 2017). People living with HIV have a higher chance of developing a gastrointestinal disturbance such as celiac disease and lactose intolerance which could cause the women to avoid certain foods.

### **HIV Prevention Interventions for African American Women**

While individual behavioral factors are strong predictors of HIV infection, it is important to acknowledge the impact of environmental factors as it relates to increased HIV risks. All of the women lived in improvised neighborhoods. The environment can determine an individual's socioeconomic status (SES) which is driven by many factors, including education, employment, and income. There remains little research on the effectiveness of structural interventions that address SES in efforts to reduce HIV transmission. Most of the research on interventions focus on individual behavioral factors in reducing HIV transmission. Incarceration was also a common theme throughout this research. In this country, African American men are disproportionately incarcerated which destabilizes the Black community. Therefore, creating creative approaches to reduce HIV risk through policy reforms to eliminate sentencing disparities and reduce disproportionate incarceration rates among African Americans and effective initiatives that focus on childhood enrichment could help address economic inequality. Due to the complex interaction of individual and environmental factors, it is imperative to evaluate variables from each of the categories to determine their independent impact on HIV risk among African American women. This will help public health professionals identify areas where prevention efforts will be most effective and development of new prevention strategies.

At the individual level, combining educational programs with another chronic disease such as



diabetes might help normalize HIV prevention. Although diabetes and HIV are chronic diseases that have dangerous complications, diabetes is socially accepted among the Black community. Social support and stigma in the Black community has incredible influence on health and prevention. There is a need to create partnerships with individuals living and working within the Black community that care and invested in the health of Black Americans such as faith-based organizations. The goal is to bring various perspectives, insights, and experiences together to ensure the most informed understanding HIV and diabetes phenomena in the Black community (Zuniga et al., 2018). This will help guarantee meaningful, culturally appropriate interventions and programs. This partnership will also empower participating community members with health promotion and disease prevention abilities.

### **Combating HIV Stigma in Healthcare Professionals**

Stigma and implicit bias among healthcare professionals has a profound effect on retention in care among African American women people living with HIV. Research shows there are three main preventable causes of HIV-related stigma in the healthcare setting: lack of awareness among health workers of what stigma looks like and why it is damaging; fear of casual contact stemming from incomplete knowledge about HIV transmission; and the association of HIV with improper behavior. Along with HIV-related stigma, many women experience perceived discrimination from their healthcare providers. Many women do not return to that provider or fall out of care when they are comforted with these experiences. Therefore, it is important to combat stigma and discrimination within healthcare facilities.

At the individual level training should focus on increasing awareness what stigma is and allow

for critical reflection of implicit and explicit bias among them. Individual level interventions should also focus on understanding HIV transmission along with universal precautionary methods to alleviate fears. During this part of the intervention, shame and blame directed at women living with HIV needs to be addressed. Policy level interventions are necessary to reinforce behavior change and to create environments that inhibit discrimination. This could include implementing a system to receive feedback and experiences with stigma. Concurrently, delivering trainings for medical staff that focuses on increasing awareness and potential biases are not only opportunities for professional development but may have a direct impact on patient outcomes. Such approaches have been advocated for, specifically given the numerous barriers that African American women encounter (Watkins-Hayes et al., 2012).

### **HIV Treatment and Support Programs for African American Women Living with HIV**

Given that HIV impacts all aspects of health, particularly nutrition, there is a critical need to incorporate Registered Dietitians as part of the HIV care continuum. As indicated within this study, given the number of health concerns physicians attend to during a single medical visit nutrition is often overlooked. Thus the Registered Dietitian Nutritionist are professionals that are well versed in disease states that affect the gastrointestinal tract and require increased energy needs are rarely consulted with for HIV patients. It is crucial for someone living with HIV to receive all essential nutrients to prevent muscle and weight reduction and sustain the immune system. Healthcare facilities serving people living with HIV should have a Registered Dietitian on staff to train doctors and consult with patients.

To address nutrition and other health outcomes among this population, social support remains

critical. Successful models of support group programs for African American women have been well documented within the literature (Carmen et al., 2016; Kovach, 2008; Robillard et al., 2017; Watkins-Hayes et al., 2017). Based on the current findings, these programs when delivered to those living with HIV could be tailored to include training on providing mentorship and education within the community. Doing so provides mutually beneficial opportunities within the community. Specifically, women gain self-empowerment skills while providing necessary education outreach within the community.

### **Limitations**

This study is not without limitations. The most significant limitation of this study was the sample size. A larger sample size would allow for more experiences and understanding. Although majority of people living with HIV reside in the South, there was no comparison group with women who live in other regions. Future research is needed on HIV/AIDS experiences of women living in Northern, Western and Eastern states in order to gain more insight into cultural differences and much more rich descriptions of similarities and differences of living with HIV/AIDS. Nonetheless, the women included in this study provided a glimpse into the stages toward accepting their diagnosis and moving forward in their lives.

### **Conclusion**

This phenomenological study was conducted to understand the experience of living with HIV as an African American woman along with the nutritional impact the disease is having on their immune system. As seen in this research, including a nutrition professional in the HIV care process is vital to ensure the immune system works properly. Although, the use of marijuana as appetite

stimulant was not as pronounced as the other themes, it should be taken into consideration to aid in food intake. The women, within their experiences, demonstrate resiliency in their ability to overcome structural and cultural barriers within their communities. There remains a critical need to address the proximal and distal determinants that impacts health outcomes among African American women living with HIV. Failure to do so will place these communities at further risk.

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## APPENDICES

**Table 1. Sociodemographic Characteristics of the Sample (n = 7)**

Age		47.4	12.15
Race/ethnicity			
Black/African American	7	100.0	
White, non-Hispanic	0	00.0	
Native American/Alaskan	0	00.0	
Other race/ethnicity	0	00.0	
Education			
Less than High School Diploma/GED	1	14.0	
High school graduate	2	29.0	
Some college or technical school	3	43.0	
Undergraduate degree	1	14.0	
Graduate degree	0	00.0	
Personal income			
\$30,000 or less	6	86.0	
\$30,001 to \$50,000	1	14.0	
\$50,001 to \$80,000	0	00.0	
More than \$80,000	0	00.0	
Employment status			
Full-time (35+ hours per week)	1	11.0	
Part-time	1	11.0	
Part-time student	1	11.0	
Unemployed (Looking for work)	2	22.0	
Not in workforce	4	44.0	
Relationship status			
Single	5	71.0	
Married	1	14.0	
Divorced	0	00.0	
Widowed	1	14.0	

Sexual orientation				
Heterosexual	6	86.0		
Bisexual	1	14.0		
Children/dependents				
0	2	29.0		
1-2	3	43.0		
3-4	1	14.0		
5-6	1	14.0		
Governmental Benefits				
Medicaid	5	42.0		
Blue Cross	5	42.0		
Supplemental Nutrition Assistance Program (SNAP)	0	00.0		
Temporary Assistance for Needy Families (TANF)	0	00.0		
Disability	1	08.0		
Ryan White	1	08.0		
Residency				
Oklahoma	2	29.0		
Texas	2	29.0		
Georgia	3	42.0		

**Table 2. Emerging Themes and Subthemes**

Subthemes	Main Themes
<ul style="list-style-type: none"> <li>• Diagnosis experience:               <ul style="list-style-type: none"> <li>○ Initial, shock, denial, anger, depression, and then acceptance</li> </ul> </li> <li>• A New Me: Empowerment of Self and Others</li> </ul>	Moving Beyond and Acceptance
<ul style="list-style-type: none"> <li>• Internalized stigma</li> <li>• Stigma from health care providers</li> <li>• Stigma from family and friends               <ul style="list-style-type: none"> <li>○ As a woman</li> </ul> </li> </ul>	Experiencing Stigma
<ul style="list-style-type: none"> <li>• Family and friends</li> <li>• Healthcare providers</li> <li>• Support groups               <ul style="list-style-type: none"> <li>○ Coping mechanisms</li> </ul> </li> </ul>	Social Support and Relationships
<ul style="list-style-type: none"> <li>• Family/friends</li> <li>• Workplace</li> <li>• Healthcare setting</li> </ul>	Discrimination
<ul style="list-style-type: none"> <li>• Cultural competency</li> <li>• Mental health</li> <li>• Lack of nutrition information</li> </ul>	Quality of Healthcare

APPENDICES

Number/Alias

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**African American Women Living with HIV and their Nutritional Implications**

QUESTIONNAIRE

This is a study about being an African American woman living with HIV and nutritional deficiencies. In this questionnaire you will be asked several personal questions; however, all your answers will **remain confidential** to the full extent allowed by law. Therefore, please read the questions carefully, and please answer truthfully and accurately. Your participation in this study is very important for my research and is **greatly** appreciated!

**PLEASE DO NOT WRITE YOUR NAME ANYWHERE ON THIS QUESTIONNAIRE.**

**Q1. What is your current age in years? (Please write in numbers.)**

\_\_\_\_\_ years old.

**DIRECTIONS:** For each of the following questions, please **circle the number** corresponding to your response. **Circle only one response per question.**

**Q2. What is your current marital status?**

- 1.....Single
- 2.....Married
- 3.....Domestic Partnership
- 4.....Separated
- 5.....Divorced
- 6.....Widowed

**Q3. How many children do you have?**

**Q4. What is your highest level of completed education?**

- 1..... Less than High School Diploma/GED
- 2..... High School Diploma/GED
- 3..... Some College or Technical Trade Schooling
- 4..... Completion of Undergraduate Degree
- 5..... Graduate Degree (e.g., MA, MS, MBA, PhD, MD)

**Q5. What is your current annual household income (before taxes)?**

- 1.....\$29,999 or Less
- 2.....\$30,000-\$49,999
- 3..... \$50,000-\$79,999
- 4..... \$80,000 and Above

**Q6. What is your current employment status?**

- 1..... Employed Full-Time (35+ hours per week)
- 2..... Employed Part-Time (Less than 35 hours per week)
- 3..... Full-Time Student
- 4..... Part-Time Student
- 5..... Unemployed (Looking for work)
- 6.....Not in Workforce (Not looking for work)

**Q7. How would you define your sexuality or sexual orientation?**

- 1..... Heterosexual/straight
- 2..... Bisexual
- 3..... Gay/Lesbian or Homosexual
- 4..... Unsure

**Q8. Which benefits are you currently enrolled in? (Check all that apply)**

- ..... Medicaid
- ..... Blue Cross
- ..... Supplemental Nutrition Assistance Program (SNAP)
- ..... Temporary Assistance for Needy Families (TANF)
- ..... Women, Infants, and Children Food and Nutrition Service (WIC)

**Other:**

**Q9. What state do you live in? \_\_\_\_\_**

**Q10. Please list the month and year of your last HIV/AIDS test (Please specify in month/year format).**

\_\_\_\_\_/\_\_\_\_\_

**End of Questionnaire. Thank you for your time!**

## Interview Guide

### **Study Title:**

### **African American Women Living with HIV and their Nutritional Implications**

#### **Introduction**

Good morning/afternoon/evening. Thank you for agreeing to be apart of this study. My name is Esosa and I will be asking you a few questions about your experience. Your thoughts and comments are very valuable to my research.

#### **Purpose**

The purpose of this research is to increase understanding of the experience of being an African American woman living with HIV and nutritional deficiencies you may have. Interviews will be conducted on an one-on-one basis and will last approximately 45-60 minutes. During these interviews, questions will be asked regarding your experience, feelings, and behaviors about stigma, your relationships, healthcare treatment, and nutritional adherence. There are no right or wrong answers, so please feel free to speak your mind when questions are asked. The interviews will be audio recorded and transcribed for research purposes.

I am conducting this interview as a graduate student at Oklahoma State University.

The results will be used for research purposes in completion of my master's level thesis study. This knowledge will be helpful for health care providers and program planners to better understand how to help African American women with HIV and prevention efforts.

#### **Procedure**

Before we continue, I need you to read consent form regarding your rights and the process of the study. If you have any questions please, feel free to ask me. If you agree to continue the process of this study, please date, print and sign your name below.

**(Give participant consent to participate form. Upon completion, continue.)**

Thank you. As a reminder, I will be recording and taking notes. Feel free to leave or not answer any questions that you choose not to. Now, I would like to give you a short questionnaire to get demographic information about the people that I am interviewing. At the top, you will write the number that you are assigned and create an alias of your choice.

**(Give participant questionnaire. Upon completion, continue.)**

Thank you for filling out the questionnaire. Now, we will start the interview process. Again, answer as feeling as you would like.



## Consent Form

### INFORMATION SHEET & INFORMED CONSENT

Study Title: **African American Women Living with HIV and their Nutritional Implications**

#### **Background:**

You are invited to participate in a research study directed by Esosa Osagiede to investigate life experiences of African American women living with HIV and their nutritional implications. The faculty advisor for this study is Dr. Randolph Hubach, Assistant Professor at Oklahoma State University.

#### **Purpose:**

The purpose of this study is to gain understanding of the life experiences of African American women living with HIV. This knowledge will be helpful for health care providers and program planners to better understand how to help African American women with HIV and prevention efforts.

#### **Description of Interviews:**

Participation in the study involves completion of a short demographic data questionnaire (e.g., age, race/ethnicity, education level) and one interview, which will last for approximately 45-60 minutes. The interviews will be conducted at a setting that is mutually agreeable to the participant and the researcher. The interview will consist of the interviewer (Esosa) asking open-ended questions and listening to your feedback. The interview sessions will be audio recorded to ensure that I am able to capture all of the information.

#### **Benefits of Participation:**

You may benefit from being able to candidly speak about your experiences within a comfortable and non-judgmental environment. However, if you do not directly benefit, results from this study may improve the lives of African American women by improving treatment and bringing awareness HIV prevention in the African American community.

#### **Confidentiality:**

All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. You will be identified as an alias of your choice.



## Interview Questions

<b>Domains</b>	<b>Questions</b>	<b>Probes</b>
<b>Social Support</b>	What does your community mean to you?	1. Church 2. Friends and family
	How does your community impact your health?	
	Who is the person that you can say has your back or best interest no matter what?	How do they support you?
	Do you feel like you have social support system since your diagnosis?	1. HIV organizations 2. family/ friends
<b>Stigma/HIV-related stigma</b>	Tell me about your life prior to getting HIV?	1. Romantic relationships . Work 3. Family structure and relationships . Friend relationships
	How does your condition impact your relationships?	1. Family members, children, society, religious beliefs
	Do you experience any stigma related to HIV?	1. friends 2. family
<b>Healthcare</b>	Can you describe your relationship with your doctor or any other provider?	
	Have you ever felt uncomfortable or unsure with asking your doctor any questions regarding your HIV?	If yes, what usually stops you from bringing up an issue or starting a conversation?
	Has your doctor recommended any nutritional advice regarding helping your immune system or side effects of your medication?	1. What was the advice? 2. Has your doctor ever referred a Dietitian Nutritionist?

	Did you change your diet after your diagnosis?	<ol style="list-style-type: none"> <li>1. Food safety</li> <li>2. Symptoms affecting your diet</li> <li>3. Eating more nutrient dense foods</li> <li>4. Any barriers to a nutritious diet</li> </ol>
<b>Barriers to care</b>	What barriers do you come across when trying to care for yourself and the HIV?	<ol style="list-style-type: none"> <li>1. Income</li> <li>2. Environmental</li> <li>3. Being a single parent (if a single parent)</li> <li>4. Food desert</li> </ol>
	What are some of the difficulties that you encounter in keeping your appointments?	
	Do you ever feel you have to sacrifice taking care of yourself for others?	
<b>Discrimination</b>	Have you ever felt like your being treated unfairly?	
	How do you feel about the people who treated you unfairly?	

## Participants Needed

If you are an African American woman living with HIV, age 18+ years old,  
please consider your participation.

Please contact:

Esosa Osagiede

[esosagiede@okstate.edu](mailto:esosagiede@okstate.edu)

214.299.1410

Or

Randolph Hubach

[randolph.hubach@okstate.edu](mailto:randolph.hubach@okstate.edu)



The **goal** of this study is to understand the health needs of African American women living with HIV. Your participation will help healthcare professionals meet the public health needs of your community.

The study will include a 45-60 minutes one-on-one interview.

Participation is voluntary and **confidential**.

A \$20 Amazon gift card will be given to each participant for appreciation of time and effort.

If you have any questions, please contact Esosa Osagiede or Randolph Hubach

VITA

Esosa Osagiede

Candidate for the Degree of

Master of Public Health

Thesis: AFRICAN AMERICAN WOMEN LIVING WITH HIV AND THEIR  
NUTRITIONAL IMPLICATIONS

Major Field: Public Health

Biographical:

Education:

Completed the requirements for the Master of Public Health at Oklahoma State University, Stillwater, Oklahoma in May 2019

Completed the requirements for the Bachelor of Science in Nutrition emphasis in Dietetics at Texas Woman's University in Denton, Texas, United States, May 2017

Experience:

Graduate Teaching Assistant August. 2017 –Current

Oklahoma State University

- Collaborate with a team of faculty at monthly meeting and actively contributed new ideas on teaching
- Responsible for grading assignments, class participation, and exams
- Consistently recognized for academic excellence through teaching
- Successfully balance student workload while teaching Health and Wellness lecture for 150 students
- Create interactive role-playing exercises and group presentations to improve student participation and diversity understanding

Professional Memberships:

- Academy of Nutrition and Dietetics