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# HIV POSITIVE WOMEN OF COLOR IN URBAN AREAS OF SOUTH CAROLINA WHO ARE NOT IN CARE

BY

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Degree to be awarded: M.P.H.  
Executive MPH

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M.P.H., Emory University, 2016  
M.S.W., Clark Atlanta University, 1995  
B.S., Francis Marion University, 1993

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An abstract of a Thesis submitted to the Faculty of the Rollins School of Public Health  
of Emory University in partial fulfillment of the requirements of the degree of  
Master of Public Health in the Executive MPH program  
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## Abstract

# HIV POSITIVE WOMEN OF COLOR IN URBAN AREAS OF SOUTH CAROLINA WHO ARE NOT IN CARE

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Women of color living continue to be greatly impacted with HIV/AIDS compared to their white counterparts. HIV/AIDS is the 4<sup>th</sup> leading cause of death among African American women ages 35 to 44 years old. According to the treatment cascade, many people living with HIV/AIDS are aware of their status but are not actively engaged in HIV care.

The state of South Carolina ranks 10<sup>th</sup> in the number of HIV/AIDS cases in the United States. According to the state's Division of Surveillance and Technical Support, there were just over 3800 African-American women living with HIV/AIDS at the end of 2014. The rates of HIV/AIDS among women of color are far greater than those of their white counterparts (742). The state's Epidemiological Profile also surprisingly shows there are more people not in care who reside in urban areas of South Carolina than those living in rural areas.

The study explored social determinants impacting the decision of urban women of color living with HIV/AIDS to not seek HIV medical care. The study participants were engaged in an in-depth interview to discuss their perceived stigma in healthcare settings, the impact of a lack of social and family support as well as depression.

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I also dedicate this body of work in the memory of cousin, Chenier M. Smith, who lived with HIV/AIDS for nearly 12 years. His encounters with the healthcare systems and the stigma he faced throughout his life inspires me to provide the best care and support to others fighting the same battle.

I also dedicate this body of work in the memory of my dear aunt, Florence B. Brown. As an educator in the public school system for over 42 years she and my mother Rosalind R. Rivers were my first teachers. Aunt Florence helped to instill in me the value of education. She also taught me the value of hard work and persistence.

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## Chapter 1: Introduction

The Centers of Disease Control (CDC) released a report in 1981 regarding cases of a rare lung disease, Pneumocystis carinii pneumonia (PCP) among gay men in California. By year's end there were reports of 270 cases of gay men with severe immune deficiency; nearly half of them had succumbed to their illness. HIV/AIDS quickly became known as the gay man's disease[1]. In 1982 the CDC began using the term "AIDS" (acquired immune deficiency syndrome) and released the first case definition. By 1992, AIDS became the number one cause of death in the United States among men ages 25 to 44[2].

Seventeen years after the genesis of HIV/AIDS, the face of the disease has changed dramatically. Of all racial and ethnic groups African Americans are most impacted by the disease. In 1992 AIDS-related mortality for African Americans was nearly 10 times that of Whites and three times that of Hispanics[2]. The CDC reported African Americans accounted for 49% of AIDS-related deaths in the United States in 1998[2]. In 2010, the CDC reported that African Americans still accounted for 44% of all newly diagnosed HIV cases[2].

While African Americans are at highest risk based on race, one in four people in the United States living with HIV are women[1]. Of all the women living with HIV, it is estimated that only 88% of them have been diagnosed. Of those diagnosed with HIV, only about a third of them have the virus suppressed. In 2011, 23% of all people living with HIV were African American and Hispanic; these women of color continue to be disproportionately impacted by HIV[1].

According to the South Carolina Department of Health and Environmental Control (SC DHEC), women of color constitute 15% of the state's population and they are also 24% of all South Carolinians living with HIV/AIDS. In South Carolina during the years 2012-2013, forty-seven percent of newly diagnosed heterosexual HIV/AIDS cases were African-American women[3]. SC DHEC reports eight out of every ten women under the age of 25 living with HIV/AIDS are African American.

South Carolina's HIV Epidemiologic Profile surprisingly reports 73% of South Carolinians living with the virus who are not engaged in HIV care reside in urban areas of the state. The profile reports 64% of women of color living with HIV/AIDS reside in urban areas of the state and nearly a third of them are not in care[3]. With such a significant number of African-American women not engaged in HIV care it is less likely their viral load would be suppressed therefore making it more likely to transmit the virus to others. According to Israelski *et al.*, in agreement with several other researchers, the lack of HIV care is associated with faster disease progression and the development of drug resistant strains of HIV[4-6].

The Deep South is historically known for its promotion of slavery[7-9]. Experts believe the culture and history of the Deep South possibly endorses a climate that facilitates the spread of diseases through distrust of the healthcare system[7]. Reports suggest African Americans experience feelings of distrust due to bias, stereotypes, and prejudice on behalf of the healthcare providers[8, 9]. Often times African Americans perceive the act of health seeking behaviors as a demeaning and embarrassing experience[9].

## Purpose Statement

Although much is known about the barriers to HIV care, this qualitative research study examines the factors impacting women of color living with HIV/AIDS who reside in urban areas of South Carolina who are not receiving HIV care. The focus on South Carolina women of color living with HIV/AIDS can possibly provide a better perspective of why other women of color residing in the Deep South are not receiving HIV/AIDS care or do so infrequently. Considering the existing literature on barriers to HIV care, key concepts investigated in this study are the individual, health, and social factors of women of color living with HIV/AIDS who are not in care in urban areas of South Carolina such as perceived stigma in healthcare settings; lack of family and social support as well as depression. A qualitative review of these factors will help to identify the best approach to keeping HIV positive women of color residing in urban areas engaged in care. Ultimately, adherence to HIV care guidelines will lead to more women of color being prescribed antiretrovirals which will lead to suppressed viral loads therefore reducing the spread of HIV/AIDS.

## Research Questions

What are the social determinants preventing women of color living with HIV/AIDS in urban areas of South Carolina to engage in HIV care?

**Question 1:** Is perceived stigma in healthcare settings a barrier for HIV positive women of color who are not in care?

**Question 2:** Does the lack of family and social support create barriers to care for HIV positive women of color who are not in care?

**Question 3:** Does depression impact the ability of women of color living with HIV/AIDS to engage in care?

## **Significance Statement**

Women of color endure disproportionately high rates of poverty, low levels of health literacy and lack of access to high quality of HIV medical care [10]. According to Aziz and Smith, due to the aforementioned barriers, women of color living with HIV often delay entry into care and have poor outcomes [10]. In order to improve the health outcomes of women of color living with HIV/AIDS in the urban areas of South Carolina, it is imperative to gain insight into their perspectives as to what affects their ability to engage in and be retained in HIV care. Engaging and retaining women of color in HIV care is also imperative in slowing the spread of HIV/AIDS. Patients who are retained in care and started on HIV medications are more likely to obtain the goal of a suppressed viral load therefore lessening the likelihood of infecting others with the virus [1]. A review of these women's perspectives and barriers to care could lead to needed changes within the health care system and the provision of care.

## **Definition of Terms**

**CDC defined AIDS** – when the immune system of a person infected with HIV becomes severely compromised (measured by CD4 cell count) and/or the person becomes ill with an opportunistic infection.

**Healthcare disparities** – racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of interventions.

**HIV-related stigma** – refers to prejudice, negative attitudes and breaches of confidential, as well as judgement about a person's HIV status, behavior, sexual orientation or gender identity.

**Lost to care** – having less than 2 outpatient visits within a 6-month period of time.

**Prevalence rate** - the proportion of a population that has a particular disease, injury, other health condition, or attribute at a specified point in time or during a specified period.

**Social determinates of health** – defined by the World Health Organization as social determinants of health (SDH) are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

**Spirituality** – the association with well-intentioned forces and how it relates to the experiences of soul growth and a connection to a higher power.

**Urban area** - defined by the United States Census Bureau as areas with a population of more than 50,000 people.

**Women of color** - for the purpose of this paper the term “women of color” refer to African American women.

## **Chapter 2: Review of Literature**

The purpose of this study is to qualitatively examine the factors impacting women of color living with HIV/AIDS who reside in urban areas of South Carolina who are not receiving HIV care. There are numerous factors which positively and negatively influence engagement and retention in care for women living with HIV/AIDS. This chapter will present literature on factors such HIV-related stigma, mental health issues, family and social support, patient/provider relationship, and religious matters all of which impact engagement and retention in HIV care.

### **Women of Color Living with HIV Who Are Not in Care**

An overwhelming majority of women living with HIV/AIDS are African-American or Hispanic[5]. The CDC reports that African-American women accounted for 61% of all newly diagnosed HIV infections in 2014 among women; the diagnosis rates of women of color are nearly 3.5 times that of their white counterparts[11]. The majority of these infections were due to heterosexual transmission[12]. By the end of 2009, over 56% of all women living with HIV/AIDS were represented in ten large urban clusters throughout the United States[13].

Social determinants create barriers for WOC living with HIV/AIDS from becoming engaged in and retained in HIV care. Barriers to care varied throughout different studies but there was a consensus among different researchers that barriers to care fell into three categories: personal/cultural, structural, and stigma related[9, 14-16]. Some key barriers that fall into the aforementioned categories are a lack of transportation; economic factors; a drug and alcohol abuse history; clinic hours; patient/provider relationship; fear and being a minority lead to barriers[9, 14-16]. In many studies those who were not engaged or retained in HIV care were minorities, women, drug users, and poor residing in both rural and urban areas[15, 17-22].

More than half of newly diagnosed patients who delay initiating HIV care present with AIDS-defining CD4 counts of below 200[23]. In a study conducted by Box *et al.*, 41% of the female participants who delayed HIV care were diagnosed with AIDS once presenting for HIV care[24]. Racial and ethnic minorities often experience delays in HIV care engagement; this is particularly true for WOC[10, 25-29]. Cargill *et al.*, cited a study that found out of 3500 HIV positive patients, that African Americans were 56% more likely to have a greater than 3-month delay in initiating care than their white counterparts[26]. A delay in initiating care is not the only factor influencing poor health outcomes; missed appointments also play a role in poor health outcomes for WOC living with HIV/AIDS. Research shows improved health outcomes in patients who are consistently engaged in care than those who are not regardless of whether they reside in rural or urban areas[30].

Retaining WOC living with HIV/AIDS is essential to reducing the rates of premature mortality[10, 25-29]. WOC residing in both rural and urban areas who are not in care are unable to benefit from the improved HIV outcomes that result from highly active anti-retroviral therapy (HAART)[10]. HAART, which is a regimen of three or more antiretroviral drugs used in combination, has significantly improved the life expectancy of those living with HIV/AIDS[31]. Engagement and retention in care is required to benefit from being prescribed HAART which suppresses the viral load. If HIV care is not initiated within the first year of being diagnosed there is more likely to be a delay in starting HAART[23]. Fifty percent of PLWHA who delay care develop resistance to one or more of the drugs prescribed which ultimately result in the inability to suppress the viral load[17].

Retention in HIV care can also potentially reduce transmission rates. Patients engaged in care and receiving HAART experience viral suppression which dramatically decreases transmission rates[32]. The preventative role of HAART has been documented in many observational studies of HIV-discordant heterosexual couples[33]. It is estimated that when HAART is more commonly used there is a potential of a decreased HIV incidence[34].

### **Factors Impacting Engagement in HIV Care for Women of Color**

**Patient/provider relationship.** An important factor which may influence the engagement and retention in HIV care by women of color is the patient/provider relationship (PPR)[9, 26, 35-40]. Researchers believe the partnership between the patient and healthcare provider to be an integral part of the therapeutic relationship. The PPR can be a motivating factor when it comes to being compliant with the HAART regimen[14, 19, 26, 36, 41-43]. In a study conducted by Cargill *et al.*, it was found that patient satisfaction with PPR was associated with significantly higher compliance[26].

In a study by Tello *et al.*, which consisted of urban African American women, participants expected providers to be caring, passionate, understanding and honest in their evaluations and most of all respectful. It was concluded that if PLWHA sensed their needs were respected they were more likely to engage in HIV care[37]. It was found that trust of the provider was important; if the patient trusted the provider they felt comfortable sharing medical information [19, 44]. However poor patient/provider relationships and perceived low levels of respect from physicians and staff were determined to be barriers to care [37].

The patient/provider relationship is also negatively impacted by HIV-related stigma (HRS)[38, 45]. Studies have also shown that many healthcare providers to use judgmental language and inappropriate or no eye contact during their encounters with patients living with HIV[46]. Some healthcare providers made patients feel uncomfortable by taking unnecessary precautions such as double gloving or wearing protective gear when it was not necessary[47].

However, Gagnon's study which took place in an urban clinic found that HIV-related stigma in healthcare settings were episodic in nature and mostly occurred with healthcare providers who did not regularly provide HIV care[46].

WOC who participated in a study conducted by Carr *et al.*, felt health complaints were discredited by care providers or simply attributed to being HIV positive. Participants thought physicians would be more accepting of them due to the physicians' medical knowledge but found physicians reacted with fear and disgust[14, 38]. An attitudinal barrier was also identified by Dodds *et al.*, when providers in an urban clinic setting experienced burn-out especially after numerous attempts were made to encourage, educate, and engage young women in care and to adhere to medication regimens[48].

Effective communication skills were also found to be key in building a positive patient/provider relationship[36]. Enhanced communication between patients and providers allow for improved treatment outcomes[19]. A study by Kinsman *et al.*, examined the use of first person plural in patient/provider encounters in several urban clinics[36]. According to Kinsman *et al.*, the misuse of pleural pronouns like 'we' and 'our' lead to indirect communication. Providers' indirect requests of patients were perceived as not holding patients accountable for self-behaviors[36]. Patients who participated in Kinsman's study rated providers poorly in the area of communication. Patients felt those providers appeared to be persuasive; patronizing; or condescending[36].

A lack of cultural competency among healthcare providers and racial discordance between patients and providers may also negatively influence the patient/provider relationship[9, 21, 26, 39, 42]. A shortage of African-American healthcare providers perpetuates mistrust in the African-American community[26, 43]. Cargill *et al.*, in consensus with other researchers see racial discordance as one of the root causes of healthcare disparities within the African-American community[9, 26, 39]. It has been found that HIV

positive African Americans living in rural and urban areas who receive care from white providers are prescribed HAART on average 119 days later than African Americans receiving HIV care from a provider of the same race[26, 40, 43]. Patients rate care received by a provider of the same race higher than care received by a provider of a different race[9]. Previous research shows patient/provider racial concordance improves HIV health outcomes[43].

**Clinic environment.** The clinic environment can significantly impact HIV care engagement and HAART adherence[41]. In order to avoid negative clinic experiences in rural and urban areas many PLWHA reported using informal care such as emergency departments and urgent care facilities or choosing larger medical centers as well as commuting to care outside of their community all in an effort to avoid HIV-related healthcare organizations[46, 47]. In a study conducted by Chambers *et al.*, participants reported that clinic environments where PLWHA had separate waiting rooms made patients feel stigmatized[47]. Stigma within the healthcare systems affects access to HIV-related care; medication adherence; social interaction and social support which all leads to poor health outcomes for women of color living with HIV/AIDS[14].

The organizational structure and management of care facilities also present barriers to HIV care[35]. Women living with HIV/AIDS reported the desire for comprehensive services, such as women's services and lab work in one location where the clinic environment was seen as pleasant; this is particularly true of urban participants in the study conducted by Tello *et al.*,[35, 37, 41, 49]. The provision of extended clinic hours; flexible scheduling; and peer services as well as reminder calls were seen as facilitators for engagement in HIV care[35, 37]. Holtzman *et al.*, stated the use of an HIV-specialist clinical pharmacist for medication management has been also shown to improve adherence and clinical outcomes[41].

**HIV knowledge and health literacy.** Health literacy plays an important role not only in HIV prevention through understanding of risk and the identification of necessary behavioral changes but it is also integral in engaging and retaining PLWHA in care[50-53]. Hicks *et al.*, have defined health literacy as “the degree to which individuals have the capacity to obtain process and understand basic health information and services needed to make appropriate health decisions.”[51] The absence of health literacy is vital to the field of public health especially when it impedes adherence to HIV treatment which can cause incomplete viral suppression leading to drug resistance[50-52, 54]. HIV positive patients with low health literacy may not understand the repercussions of HAART non-adherence[52]. A research study conducted in an urban location by Wolf *et al.*, found low health literacy to be associated with poor knowledge on how and when to take medications; he also contends low health literacy impact those in rural areas as well[54]. Barriers to medication adherence may account for poorer health outcomes for those found to have lower health literacy skills[52].

People living with HIV/AIDS with limited health literacy may not have the cognitive skills to effectively understand or use the information to engage in HIV care as well as retain medical directives[18, 19, 50]. Studies show participants with lower health literacy skills are more doubtful of the medication benefits as well as not understanding HIV labs[50-52, 55]. In a study conducted in an urban setting by Kalichman *et al.*, showed those with lower levels of health literacy endorsed significantly more negative perceptions and experiences related to HIV care[50]. PLWHA were found to frequently develop their own understanding of the virus which influenced self-care behaviors and treatment outcome. Jones *et al.*, reported HIV knowledge to be an indicator of engagement in care. The more knowledge and understanding one possessed the more likelihood of engagement in HIV care increased[19]. Understanding the disease process has been found to be crucial to HIV care self-management[19].

**HIV-related stigma.** HIV-related stigma has been defined as the prejudicial feelings; stereotypical perceptions; discriminatory behaviors and actions or social devaluation of HIV-related illness and activities associated with PLWHA[14, 47, 56, 57]. HIV-related stigma has become one of the largest barriers to ending the HIV/AIDS epidemic[47, 58]. HIV-related stigma is associated with accessing treatment inconsistently or late in the disease process; non-adherence to HAART; and poor health outcomes[47, 58-61]. Studies have cited that newly diagnosed patients who reported perceived stigma were less likely to be retained in HIV care[62, 63]. It has also been noted that one's perception of HIV-related stigma increases when taking HIV medications[57]. Medication adherence is vital for maintaining viral suppression[18, 57]. Higher levels of perceived HRS is associated with poorer health ratings for WOC[18, 61].

HIV-related stigma experienced by women often compromises their help seeking behaviors[14, 64, 65]. Vyavharkar *et al.*, found that among rural women who report poor social support perception of HIV-related stigma increases and a negative correlation exist between HIV-related stigma and quality of life in both women in rural and urban areas [47, 57, 64]. Many factors perpetuate stigma, including lack of understanding of the illness, misconceptions about how HIV is transmitted, lack of access to treatment, and the inability to cure AIDS. HIV-related stigma and discrimination can negatively impact the health outcome of WOC[62, 64-66]. According to Wingood *et al.*, HIV positive women from both rural and urban areas who reported discrimination had higher mean scores for stress, suicidal ideation, depressive symptoms as well as lower mean scores for self-esteem and quality of life[66]. These women were found to be more likely not to seek HIV care[66]. Interestingly this study found that white women living with HIV were more likely to report HIV-related discrimination than WOC. Women of color were more likely to attribute perceived discrimination to race and not their HIV status[66]. Since racial discrimination is more

prevalent for African Americans it may be difficult to distinguish between racial and HIV-related discrimination[66]. Wingood reported WOC may find it difficult to talk about HIV discrimination therefore reporting fewer or no HIV-related discrimination. For WOC who reported HIV-related discrimination there was a consistent association between HIV-related discrimination and adverse health outcome[66]. Despite advances in HIV knowledge stigma persists to impact health outcomes; care engagement; and medication adherence.

In rural and urban areas breaches of confidentiality were viewed as stigmatizing[47]. Patients found clinic practices of labeling or color coding charts as breaches of confidentiality [47]. Often practices that seem benign to healthcare providers are perceived differently by PLWHA. Even the act of sharing information with other medical providers by word of mouth; computer; fax or written materials were all perceived as breaches of confidentiality which made patients fearful of other medical providers' reaction[44]. Whetten-Goldstein conducted a study focusing on perceived breaches of confidentiality in hospital clinics and health departments. The rural study participants chose where to seek medical care based on the degree of staff professionalism which included respecting patients' confidentiality[44]. Breaches of confidentiality have proven to be salient barriers to HIV care in both rural and urban areas for women living with HIV[37, 44, 47, 67].

**Medical mistrust.** In the African-American community, the mistrust of the healthcare system in large was caused by previous experiences and circumstances that failed to eliminate historical racial disparities dating back to the days of slavery[8, 9, 68]. According to Historian Martia Goodson, in southern medical schools, slaves were frequently used for medical demonstrations and dissections after death. Even after the emancipation of slaves, freed blacks who became acclimated to more "American" ways still used traditional African approaches to health issues[9]. They sought free care from teaching hospitals and often received inadequate care or underwent unnecessary procedures for the sake of medical

teaching[69]. In the early 20<sup>th</sup> century, many blacks who migrated to the north brought with them their beliefs about grave robbers and body snatchers which could have been related to the use of black bodies for undisclosed medical purposes[70]. The traditional practice of oral history has been passed down from generation to generation; the accounts of medical and personal violations may have influenced the trust factor for many African Americans[71].

The Tuskegee Syphilis Study has been seen as a reflection of society's disregard for the lives of African Americans[8, 69, 72]. The historically infamous study consisted of 600 African-American men in which nearly 400 of them who had syphilis went untreated for 40 years; it was the longest nontherapeutic experiment on human beings in medical history[8, 73]. Within the African-American community the legacy of the Tuskegee Syphilis Study ruined the credibility of public health officials and laid the foundation for pervasive distrust of the healthcare system[8]. Intergenerational transmission of medical care mistrust among African Americans has led to the formation of conspiracy theories[21]. HIV/AIDS conspiracy theories are extremely prevalent within the African-American community and is believed to be strongly linked to such historical events as the Tuskegee Syphilis Study[21, 69]. HIV/AIDS conspiracy beliefs are thought to be a manifestation of the mistrust African Americans have in the US government and healthcare systems[21].

Mackenzie *et al.*, developed three categories of HIV/AIDS conspiracy theories: implication of government involvement in the creation of the virus; lack of government action constitutes genocide; and the creation of medication and treatments that were meant to further do harm to the “undesirable” populations[74]. Surveys conducted within the African-American community showed strong beliefs that HIV is a man-made virus produced within American labs to kill people of color[8, 68, 74-76]. Many believe a cure is available but is being withheld by the government[74-76]. Studies show there is a belief that people who take HIV medications are being used as human guinea pigs for the government[75, 76]. A

study conducted by Bogart *et al.*, where African-American participants were randomly selected throughout the United States for an anonymous telephone survey, found conspiracy theories were more prevalent among men compared to women[75]. A study conducted by Clark *et al.*, found that 73% of African-American participants endorsed one or more conspiracy theories. Clark also found the longer one lived with the virus the more likely they were to endorse conspiracy theories; however the study was not able to confirm that people who endorsed conspiracy theories had poor health outcomes[76]. Despite Clark's findings many other researchers have confidence that HIV/AIDS conspiracy beliefs are barriers to care for those living with the virus and impact medication adherence as well as engagement in HIV care[28, 68, 75, 77].

**Family and social support.** While there are many barriers to HIV care numerous studies suggest strong family and social support have a positive impact clinically on women living with HIV/AIDS in both rural and urban areas[17, 22, 64, 78-81]. Family and social support have been positively associated with improved treatment adherence and ultimately better health outcomes for PLWHA [79, 80]. Brincks *et al.*, defined family as a “network of mutual commitment”....individuals who fill traditional family roles regardless of blood relations[82].

Family and social support were found to impact PLWHA in the areas of quality of life, self-care behaviors, and stress reduction[79, 81, 83]. A study conducted by Gielan *et al.*, suggested social support and self-care behaviors were strongly associated with health-related quality of life[78]. The study went on to suggest urban participants with large social networks have high levels of overall health-related quality of life. However, only 40% of the study's participants reported having a large social network[78]. Support from other PLWHA was found to impact quality of life[79]. Social support was found to be more important to

women because women rely on social support more compared to men in similar situations[64].

Tangible forms of social support have been shown to improve mental health status, treatment adherence, and ultimately improving health outcomes of people living with HIV/AIDS[79]. Examples of tangible support reported by study participants include picking up medications, offering help in understanding medical information, and providing a sense of belonging. Informal support provided by family and friends were identified to be a key source of resiliency often found in the African-American community[79, 80].

Positive family relationships can be a protective factor against stress[84]. Studies also indicate that WOC residing in urban areas show psychological stress was reduced efficaciously with interventions that emphasize a family-centered approach which ultimately leads to better health outcomes[80, 83]. Boeheme *et al.*, established that family support was critical to study participants for keeping clinic appointments and medication adherence. Ninety-four percent of the rural study participants felt they had adequate family support[25]. Mitrani *et al.*, also believed family-centered interventions reduced psychosocial distress for PLWHA. These sort of interventions allowed patients and their families to cope better with living with HIV/AIDS therefore allowing the PLWHA to seek the support of family[85].

A lack of family and social support are sources of stress that can be harmful clinically[82]. Some women of color living with HIV/AIDS who have a history of childhood physical and/or sexual abuse or strained family relationships experience difficulty engaging and being retained in HIV care[78, 86]. In Gielan's study, 63% of urban women living with HIV/AIDS reported being sexually or physically assaulted at least once as an adult[78]. These women tend to express concerns about stigma, discrimination and hopelessness[78, 85]. Nearly a third of women who were retained in care in a study conducted by Blank *et al.*, screened positively for experiencing intimate partner violence[22].

Brincks *et al.*, conducted a study of HIV positive women of color recruited from an urban clinic who indicated problems with stress and coping. Participants coming from families with higher than average reported stress endorsed avoidance coping (AC) behaviors [82]. AC was defined as a strategy to divert attention away from the source of stress[82]. Brincks found avoidance coping behaviors and cognitions were detrimental psychologically as well as clinically when compared to individuals with reported lower average stress[82].

Mitrani *et al.*, addressed relational factors and family treatment engagement. HIV adds an additional barrier for family engagement due to stigma which compounds secrecy and stress. Some study participants reported stigma within their families[85]. Relational barriers for participation of family members' were unavailability of family members, study participants' desire to exclude family members, and no sense of urgency on behalf of study participants to work on family problems. Researchers also identified additional barriers for family members participating in family-based interventions as negative history of African Americans and institutions as well as fear of family secrets being exposed[85]. Interestingly, Mitrani found WOC living with HIV/AIDS who reported higher levels of family hassles were more likely to have family treatment engagement...these families were more willing to air family business[85].

Whereas family and social support is critical to the ability of PLWHA to be engaged in care these relationships can become strained because of a diagnosis of HIV/AIDS. Often times women living with the virus felt they were an encumbrance to their families[22, 86]. Forty-two percent of participants in a study conducted by Blank believed being HIV positive was creating a burden to their families[22]. The sentiments of being a burden left many women feeling alone and as if their family and social support could not relate to living with HIV/AIDS. Many women in Peltzer's study expressed appearing strong on the outside but feeling fragile and confused[86].

**HIV and depression.** African American women living in rural areas overall have lower odds of meeting the criteria for major depressive and mood disorder compared with urban African American women[87]. Research as shown African-American women living with HIV/AIDS often go under-diagnosed and inadequately treated for depression in the rural and urban southeastern region[26, 88, 89]. Prevalence rates for depression are higher for PLWHA than the general population.... this is particularly true for women[64, 89, 90]. Those diagnosed with HIV/AIDS with depressive symptoms have been reported to have significantly poor HIV medication adherence; missed appointments as well as lower CD4 counts resulting in increased mortality rates[89, 91-94].

There are numerous issues associated with depression among women of color living with HIV/AIDS[66, 89]. Factors such as social support and disclosure especially to the women's children are inversely associated with depression[88]. Poor spiritual well-being is associated with significant depressive symptomology among those living with HIV/AIDS[95]. High levels of isolation have been linked to depression PLWHA[92]. Educational levels and HIV/AIDS knowledge of WOC are also highly correlated with rates of depressive symptoms[89]. Insufficient funds and financial stressors have been identified as risk factors for depression as well for all WOC living with HIV/AIDS[88, 89]. Research by Bhatia *et al.*, indicate depression and substance abuse are co-morbid psychiatric conditions recognized in PLWHA[90]. A positive correlation has been found between depression and stigma.... the more one experiences HIV-related stigma the higher the rates of depression[17, 64]. Vyavaharkar *et al.*, found that stigma impacts rural WOC's ability to disclose their HIV status which brings about feelings of isolation[17, 64]. Supportive environments provide good experiences for WOC living with HIV/AIDS to gain self-efficacy which ultimately reduces depressive symptoms[64].

Depressive symptomology among PLWHA has also been found to increase mortality and sexual risk behaviors[89]. Participants with depression in a study conducted by Dalmida *et al.*, also reported decreased quality of life[91]. Depression has been found to make it more difficult to access social support[92]. This inverse relationship is significant considering social support is key to adherence and improved health outcomes[91, 92].

It has been established that depression among WOC living with HIV/AIDS impacts medication adherence which can lead to drug resistant strains of the virus; increased morbidity and mortality; and decreased quality of life[17]. Based on research findings, there is a negative correlation between depression and CD4 cell counts; the Psychoneuroimmunology (PNI) framework has contributed to the understanding of psychological factors and physical illness[95]. Lower CD4 cell counts as a result of depression is significantly related to poor health outcomes[17, 22, 95].

African Americans living with depression and/or any other mental health disorders underutilize mental health services[94, 96]. Studies confirm insufficient use of mental health services among HIV-infected individuals[94]. A study by Reif *et al.*, examined the use of mental health services by HIV-infected adults in the Southern area of the US. HIV/AIDS Costs and Services Utilization Study (HCSUS) reported nearly one-third of PLWHA who are in need of mental health services did not receive these services[94]. Those in rural areas may be less likely to seek mental health services compared to their urban counterparts due to the stigma attached to receiving mental health services[7, 94]. A national study conducted by Villatoro *et al.*, of African Americans show a family history of treated mental health disorders more than doubles one's odds of mental health services utilization[96]. Age and educational attainment were also found to increase the odds of African Americans utilizing specialty mental health services[96]. The use of anti-depressants in conjunction with mental health

services are positively correlated with engaging in and being retained in HIV care and medication adherence[90].

**Spirituality and religion.** Spirituality and religion have historically served important roles in the African-American culture and communities[93]. Research in a southern urban area found that 85% of African Americans report religion as being an important part of their lives. More than half of the participants report attending some sort of religious service at least once a week[80]. Religious communities can be seen as a positive source of support; however, the impact of religious support on HIV medication adherence as yet to be understood[80].

Religion is known to be a core component of African-American culture in the South as well as the church being viewed as a source of support. HIV positive women who participated in adherence as well as spirituality studies reported low church attendance; but yet reported religion/spirituality as very important in their lives[17, 97]. Faith and spirituality are influential in coping skills, survival, and maintaining overall well-being and ultimately improving health outcomes for people living with HIV/AIDS[91, 93, 95, 97, 98].

Dr. Safiya Dalmida, who has conducted extensive research on spirituality and faith and its impact on people living with HIV/AIDS defines spirituality as the association with well-intentioned forces and how it relates to the experiences of soul growth and a connection to a higher power[93]. Dalmida suggests PLWHA are more likely to identify as spiritual as opposed to religious[93, 97]. Spirituality has been positively associated with health outcomes for all individuals living with HIV/AIDS as well as positive health status perception for women living with HIV/AIDS[93]. In studies conducted by Dalmida, participants affirm the importance of spirituality as a part of their lives allowing for better coping skills with family members, work issues, and personal issues as well as health practices and behaviors[93].

According to Dalmida *et al.*, 86% of WOC reported that spirituality was very important to them[98]. Spiritual acts were also found to be beneficial to those living with HIV/AIDS. Many of these WOC reported engagement in prayer; meditations; and reading religious materials on a weekly basis[98]. Dalmida correlated the frequency of reading religious materials to depressive symptoms and found that PLWHA who read more religious materials suffered fewer symptoms of depression and those who read less suffered more symptoms of depression[95]. Peltzer *et al.*, found participants often engaged in daily self-care behaviors which included prayer [86]. Prayer was seen as a powerful coping tool to help participants manage symptoms of fatigue; depression and nausea; it was also beneficial in medication adherence for many participants [17, 18, 99].

The identification of spirituality as a coping resource was extremely important to the WOC participating in Dalmida's study [98]. Spirituality as a coping resource helped with the high rates of depression which is significantly high among WOC living with HIV/AIDS. Dalmida associated higher reports of spiritual well-being with having higher CD4 cell counts[93]. Women living with HIV/AIDS who report high levels of spiritual well-being possess characteristics of behaviors associated with a better immune system[93, 98]. WOC believe through their relationship with God they are able to manage and cope with their health issues and report increased quality of life[93, 95, 97, 98].

A consensus regarding spirituality and its positive influence on women of color living with HIV/AIDS were found in several studies[17, 93, 97, 99]. In a study by Grodensky *et al.*, participants referenced their spirituality despite not being specifically asked about it. They felt it was God who helped them cope when initially learning of their HIV status and they were unable to confide in anyone else[99]. Many believed God provided the strength needed to maintain healthy behaviors and lifestyles for example being adherent to their HIV medication regimens therefore maintaining suppressed viral low loads[99].

In the lives of HIV positive women of color spirituality and faith have provided a double edged sword. Although many WOC see their spirituality and faith as a source of support it can also have a negative impact on their well-being[80, 86]. Studies conducted in southern rural areas found many believed HIV was caused by God's will and were found more likely to believe the disease progression was left up to fate[18, 99].

The African-American church has been the center of the African-American community dating back to its inception. Peltzer *et al.*, reported study participants who resided in and around metropolitan areas expressed multiple layers of betrayal from their sources of social support which included religious entities[86]. Despite a spiritual relationship with God study participants did not trust the church community[86]. Even with increased HIV/AIDS awareness and education within the African-American church community many PLWHA reported fear of having to contend with HIV-related stigma[80, 86]. A limitation cited by Peltzer *et al.*, was that these findings may not be transferable to rural populations of African-American HIV-infected women[86].

Low church attendance among WOC living with HIV/AIDS has been related to perceived HIV-related stigma within the church[97]. For those who attended church many were fearful of disclosing their HIV/AIDS status to other church members believing they would think HIV/AIDS could be transmitted through casual contact[99]. Many also feared having to experience blaming the victim encounters[80]. The experience of HIV-related stigma within the church deprive women of color living with HIV/AIDS with an important source of support[80, 99].

## Summary

Studies of PLWHA often paint a disheartening picture of the barriers to HIV care for those in rural areas. Although urban residents seem to have advantages such as close proximity to healthcare settings, public transportation and extended clinic hours there is little focus on the barriers to care for urban residents. According to Heckman *et al.*, most studies on barriers to HIV care in rural areas have not systematically assessed the direct experiences of those living with the virus or compare the experiences of those in urban areas[100]. In studies similar to that conducted by Grace *et al.*, the primary focus was on barriers of rural area residents such as lack of transportation and time traveled for appointments[101]. Little is known about the barriers that impact those residing in urban areas of the Deep South.

This study seeks to explore the barriers to engagement and retention in care with HIV positive women of color residing in urban areas of South Carolina from their personal perspectives and experiences. Previous research has examined various factors impacting engagement and retention in care of PLWHA and discovered many findings. Many of the studies conducted recruited from clinics and AIDS Service Organizations (ASO) in major urban cities that also serve patients from surrounding rural areas. Of those none were noted to distinguish their findings between participants residing in rural and urban areas. This study will provide the missing piece in addressing the issues facing women of color residing in urban areas of the Deep South.

## **Chapter 3: Methodology**

This chapter will focus on the logistics of the research study. A thorough description of the instruments used to collect data will be discussed. The chapter will also describe procedures of the study in regards to Institutional Review Board (IRB) approval; participant recruitment; interview protocol as well as questionnaire and assessment administration. In addition, this chapter will conclude with a review of the data analysis.

### **Population and Sample**

Participants consisted of a convenience sample from a list of patients from the Adult Infectious Diseases Clinic at the Medical University of South Carolina (MUSC) who met the criteria as well as from other care providers in the identified urban areas. In order to have been considered for the study potential participants met the following criteria:

1. Self-identified biologically as female
2. Self-identified as African-American
3. Must be able to communicate in English
4. Documented HIV positive test results
5. Referred to the Adult Infectious Disease Clinic for HIV medical care
6. Based on medical record review, patients must not have had a CD4 and or Viral Load lab completed in the past year or had a history of being lost to care OR patients were newly diagnosed and had not engaged in HIV care within the first 3 months of being diagnosed.
7. Based on medical record review, patients must reside in one of the following zip codes: 29201; 29203; 29204; 29205; 29206; 29209; 29210; 29212; 29222; 29223; 29229; 29401; 29402; 29403; 29404; 29405; 29406; 29407; 24910; 29412; 29414; 29418; 29420; 29464; 29466; 29492; 29601; 29605; 29607; 29609; 29611; 29615; 29617; 29730; 29732 and 29734.

## Recruitment

Potential participants were identified by running reports of known HIV positive African American female patients of MUSC's Adult Infectious Disease Clinic who reside in urban areas based on zip codes. Thirty-five potential participants were identified and a letter summarizing the study was sent out by the care providers. The letter instructed those who are interested in participating to contact the Principal Investigator (PI) by telephone to discuss the details of the study. Thirteen potential participants expressed an interest in the study. The first 10 potential participants were recruited; 9 participants were recruited from MUSC who reside in the Charleston area and 1 participant was recruited from the Columbia area.

In addition to letters being sent out from care providers to potential participants, MUSC's IRB approved flyers advertising the study to be posted around the MUSC campus. Flyers were also sent out to HIV care providers in the urban areas identified to be posted in their clinical areas. Once the potential participants made contact by telephone with the PI, the study visit was arranged with the patient where ever they were most comfortable meeting.

## Instruments

Three instruments were used in this study. The instruments were a HIV Knowledge Questionnaire; the Center for Epidemiologic Studies Depression Scale (**CES-D**) and an in-depth interview guide developed by the PI.

The HIV Knowledge Questionnaire (See Appendix A) is a nine-item self-administered questionnaire constructed by the PI regarding basic HIV questions. A review of HIV knowledge assessments such as the HIV-KQ-18[102]; Rasch Scale Model[103] and Avert's General HIV Knowledge Quiz[104] was done to determine questions for the instrument. The nine questions measure the participants' knowledge of the disease history; transmission; and disease progression.

The Center for Epidemiologic Studies Depression Scale (CES-D) form measures the current severity of the participants' depression symptoms (See Appendix B). Validity and reliability were similar across a wide range of demographic characteristics in general population samples tested[105]. This non-diagnostic screening tool consist of 20 items; responses range from 0 (rarely or none of the time) to 3 (most or all of the time) [57]. The CES-D is a short self-report scale. CES-D scores range from 0 to 60, with higher scores indicating symptoms of depression. Scores ranging from 16 to 26 are indicative of mild depression and scores of 27 and above are indicative of major depression [105].

The in-depth interview was developed and administered by the PI (See Appendix C). In addition to gathering pertinent demographic information, in Section I, for each participant the in-depth interview was used to assess various aspects of the participants' life. Section II focused on the participants' life with HIV/AIDS. Questions centered around details of their diagnosis; engagement in HIV care experience and support. In Section III, the interview questions focused on the participants past healthcare utilization and experience with healthcare providers. Illness perception and stigma were the focus of the questions in Section IV. The questions in Section V assessed the participants knowledge of HIV resources.

## **Procedures**

Once consents were obtained, the participants were given the HIV Knowledge Questionnaire and CES-D to complete. The self-administered instruments took approximately 20 minutes to complete. The PI was available to the participants during the completion of the instruments. Immediately upon the completion of the instruments the participants were engaged in an in-depth interview with the PI. Prior to starting the interview, the participants verbal consent to having the interview audio recorded for later transcription as detailed in the consent to participate. On average, the interviews took about one hour to complete. The study visit was conducted in a location the participant identified

as comfortable and provided the most privacy. Participants received a \$100 pre-paid Visa card upon completion of the study visit which was funded through the South Carolina Clinical and Translational Research Institute.

All links to the participants' information were removed. Data collected from the Knowledge Questionnaire and Depression Scale were entered into MUSC's RedCap system, a secure web-based application designed exclusively to support data captured for research studies. No identifiable information was associated with the data collected. The recorded interviews were downloaded by the PI onto a password protected computer, transcribed verbatim and then stripped of all identifying information.

### **Data Analysis Methodology**

This mixed methods study sought to determine what social determinants prevent women of color living with HIV/AIDS in urban areas of South Carolina to not be engaged in HIV care by proposing three key questions: (1) Is perceived stigma in healthcare settings a barrier for HIV positive women of color who are not in care? (2) Does the lack of family and social support create barriers to care for HIV positive women of color who are not in care? (3) Does depression impact women of color living with HIV/AIDS abilities to engage in care?

The Statistical Package for the Social Science (SPSS) 23 for Windows was used to provide descriptive analysis of the data collected. NVivo 11 Starter for Windows was used to complete the qualitative analysis of the in-depth interview transcripts and develop themes. In-depth interviews captured the lived experiences of each study participants. The qualitative content analysis of the in-depth interview used both deductive and inductive coding processes. Audio recordings of each interview were listened to twice and a third time for transcription by the PI. The PI coded as well as double coded the transcriptions to ensure all codes were identified and applied appropriately since the use of a secondary coder was not

feasible for this research project. Initial codes (See Table 1) were developed based on the interview guide questions. However, upon review of the transcripts more codes and sub-codes inductively emerged, such as trauma and history of child abuse and mothering. Upon code completion the transcripts were reviewed for recurring themes. The thematic analysis of the participants' experiences living with HIV creates a more transparent perspective as to difficulties experienced that hamper engagement in care.

**Table 1**  
*Initial Codes*

<b>Initial Codes</b>	<b>Meaning</b>
Conspiracy	Awareness and/or belief in HIV Conspiracy Theories
Depression/Mental Health	Reported feelings of sadness/depression and/or being diagnosed with a mental health disorder
Faith/Spirituality	Belief in a higher power; participation in religious acts such as church attendance, prayer or meditation
Family/Social Support	Involvement or non-involvement of family, friends and others living with HIV/AIDS
HIV-related Stigma	Perception of being mistreated based on one's HIV status
HIV & Support System Knowledge	Basic HIV knowledge as well as knowledge of available support services for persons living with HIV/AIDS
Patient/Provider Relationship	Perspective of relationship and encounters with HIV physicians and ancillary providers within the healthcare setting

## **Chapter 4: Results**

The following chapter presents an analysis of this qualitative exploratory research study, which sets out to address the primary research questions: What are the social determinants preventing women of color living with HIV/AIDS in urban areas of South Carolina to engage in HIV care? Is perceived stigma in healthcare settings a barrier for HIV positive women of color who are not in care? Does the lack of social and family support create barriers to care for HIV positive women of color who are not in care? Does depression impact the ability of women of color living with HIV/AIDS to engage in care? This chapter will include data collected from completed screening tools and questionnaires as well as in-depth interviews conducted with women of color living with HIV/AIDS.

### **Key Findings**

**Demographic and clinical characteristics of participants.** Ten women of color living with HIV/AIDS who reside in urban areas of South Carolina were recruited and fully participated in this study. All of the participants identified as African American. Nine of the 10 participants reside in the Charleston and North Charleston area of South Carolina. The mean age of the participants was 36.8 years. Forty percent of the participants never completed high school. The average annual income of the participants was \$10,582. Table 2 summarizes the participants' demographic information.

Table 2  
*Participants' Demographics*

<b>Age Range</b>	<b>(N)</b>	<b>Percent</b>
18-24	2	20.0
25-44	5	50.0
45 plus	3	30.0
<b>Educational Level</b>		
Less than high school graduate	4	40.0
High school graduate/GED	3	30.0
Some college	3	30.0
<b>Income Range</b>		
\$0 - \$5,000	2	20.0
\$5,001 - \$10,000	5	50.0
\$10,001 - \$20,000	2	20.0
\$20,001 plus	1	10.0
<b>Insurance</b>		
None	1	10.0
Medicaid	6	60.0
Medicaid and Medicare	3	30.0
Private	0	0.0
<b>Current Relationship Status</b>		
Never Married	2	20.0
Significant Other	6	60.0
Legally Separated	1	10.0
Divorced	1	10.0
<b>Urban Areas of Residence</b>		
Columbia	1	10.0
Charleston	3	30.0
North Charleston	6	60.0

In addition to participants' demographic information, clinical data were also collected.

The number of years living with HIV/AIDS varied among participants from nearly three years to 18 years. The average number of years living with HIV/AIDS was 8.5. Sixty percent of the participants were identified as CDC defined AIDS. Only 30% of the participants had undetectable viral loads at the time of the study.

As shown in Table 3, participants' care status data were collected as part of the clinical information. Participants were placed into three Not In Care (NIC) status categories:

1. late care - HIV care initiated 3 months or more after being diagnosed
2. inconsistant care - periods of 6 months or more without being seen by an HIV care provider
3. late/inconsistent care - a combination of the aforementioned categories

The majority of the participants fell into the category of inconsistent care. Four out of six participants living with AIDS spent more than 50% of the time since diagnosis not receiving HIV care. The average amount of time for the participants to not receive HIV care was 6.3 years.

Table 3  
*Clinical Demographics*

HIV Status	(N)	Percent
HIV positive	4	40.0
CDC defined AIDS	6	60.0
<b>CD4</b>		
40 and below (non-detected)	3	30.0
41 – 200	1	10.0
201 – 500	1	40.0
501 and above	5	30.0
<b>Viral Load</b>		
200 and below	3	30.0
201 – 500	4	40.0
501 and above	3	30.0
<b>Number of Months Living with HIV/AIDS</b>		
Less than 60 months	3	30.0
61 – 120 months	3	30.0
121 months and above	4	30.0
<b>Number of Months Out of HIV Care</b>		
Less than 60 months	5	50.0
61 – 120 months	3	30.0
121 months and above	2	20.0
<b>Not in Care (NIC) Status</b>		
Late	3	30.0
Inconsistent	5	50.0
Late/Inconsistent	2	20.0
<b>Percentage of Time NIC Since Diagnosis</b>		
50% and below	4	40.0
51% - 75%	3	30.0
76% and above	3	30.0

**HIV knowledge questionnaire.** Along with the collection of participants' demographic and clinical information their HIV knowledge was assessed. Each participant completed an HIV Knowledge Questionnaire to measure their general knowledge of the disease history, transmission, and progression. The questionnaire consisted of 9 multiple choice questions (Appendix A). The scores ranged from high, mid, and low as shown in Table 4. None of the participants scored a perfect 9 out of 9. The majority of the participants (60%) scored in the mid-range of 4-6 correct out of 9. Thirty percent scored in the high range and 10% of the participants scored in the low range.

Table 4  
*HIV Knowledge Questionnaire*

HIV Knowledge Scores	(N)	Percent
High Range (7-9)	3	30.0
Mid-Range (4-6)	6	60.0
Low Range (0-3)	1	10.0

**Depression/CES-D scale.** In an effort to determine the participants' level of depression they completed the Center for Epidemiological Studies (CES-D) Depression Scale. CES-D scores range from 0 to 60, with higher scores indicating symptoms of depression. Scores ranging from 16 to 26 are indicative of mild depression and scores of 27 and above are indicative of major depression [105]. As shown in Table 5, five out of the ten participants scored 16 or above indicating depression symptomology.

Table 5  
*Depression Data*

<b>CES-D Scores</b>	<b>(N)</b>	<b>Percent</b>
Less than 15	5	50.0
16 - 26	3	30.0
27 and above	2	20.0
<b>Depression Diagnosis</b>		
Yes	6	60.0
No	4	40.0
<b>Depression Diagnosed Before or After HIV Diagnosis</b>		
Before	3	50.0
After	3	50.0
<b>Mental Health Care Received</b>		
Yes	5	84.0
No	1	16.0
<b>Compliant to Mental Health Care and Medication</b>		
Yes	1	20.0
No	4	80.0

Fifty percent of the participants' scores on the CES-D Scale indicated symptoms of depression. However, during the in-depth interviews 60% of the women reported having a history of being diagnosed with depression. As one participant stated:

*Yes, I've been told before I got HIV that I suffer from depression. I go to Charleston Mental Health. I do go for one on one counseling. They told me that I have depression, paranoid schizophrenia, manic bi-polar, and postpartum depression. (Gail, 38)\**

Notably, reported depression may not be due exclusive to HIV status. Half of those with depression were diagnosed prior to learning their HIV status. Among participants with CES-D scores indicating depression symptomology, only 20% had a CD4 count below 200 and 40% with CDC defined AIDS statuses.

\*names have been changed

Eighty-four percent of the study participants who were diagnosed with depression reported receiving mental health care. This percentage is slightly higher than the 67% receiving mental health care as reported in the HIV/AIDS Costs and Services Utilization Study (HCSUS) [94]. However only 20% of this study's participants who received mental health care were compliant with the mental health care and medications. One participant expressed her inability to be receptive to mental health treatment.

*The one main reason I dropped out of care was the mind. The mind is very powerful. So it's really a battle for me in my mind to accept it. Living with HIV is hard. I tried counseling with X just to go talk to her and whatever but that doesn't do anything for me. She wanted me to take Prozac...that thing is still in my cabinet.... along with all my other medicines. What makes them think if I wasn't taking HIV meds that I was gonna take meds for depression? I never took one pill. (Linda, 34)*

### **In-depth participant interviews**

**Patient/provider relationship.** As an important factor that influences engagement and retention in HIV care, patient provider relationship was discussed during the in-depth interview. Seven of the ten participants mentioned trust specifically. Forty-three percent expressed a great deal of trust in their health care providers. The other 57% of those mentioning trust did so in a negative manner; for example one woman said the following:

*I don't really trust the healthcare system.... I always think this is a hoax you know. (Linda, 34)*

Confidentiality was also a key factor influencing patient provider relationship and several participants expressed concerns about this. Two of the participants were mothers of children who were perinatally infected with HIV. Both shared concerns of trust and confidentiality pertaining to seeking HIV care particularly for their children.

*My level of trust in the healthcare system was non-existent especially when it came to my baby. I didn't trust those doctors at all.... (Miranda, 36)*

*I was especially afraid of coming to medical appointments for my daughter because I know so many people who work here I was afraid they would figure out what was up and talk my business. (Gaynetta, 40)*

In regards to confidentiality another participant discussed rumors of leaked information pertaining to HIV positive patients from the local health department as a reason not to see her HIV care provider.

*I overheard someone say that the DHEC office has a so called list of people with HIV and that was another reason I just kinda stayed away from the doctor. (Amber, 25)*

Although the majority of the participants shared positive perceptions of encounters with their HIV care providers, a significant minority, 40% of the participants expressed negative or mixed perceptions of encounters with their HIV care providers. A respondent shared what she observed when seeing her HIV provider while another explained seeking care elsewhere.

*When I go see my doctor...you know how you can see little things? I see little things that's in her. Like the touching part. She touches me but it seem like it's only to examine me. She don't shake my hand or just you know touch your shoulder or arm just to ask how I'm doing. Why would you want to be an HIV doctor if you can't be around it? (Sandy, 42)*

*I just feel like the doctors me and my child saw here in Columbia thought they were better than us. They made me feel like I was ignorant. I see how much better my child is doing with the doctors in Charleston and they treat me so good. They explain everything so that I can understand it. It's because of them that I'm thinking about going back to the doctors but not here in Columbia but in Charleston. (Miranda, 36)*

**Conspiracy.** The belief of HIV conspiracy theories were also discussed during the in-depth interviews. Ninty percent of the participants endorsed beliefs in conspiracy theories surrounding HIV/AIDS in the African-American communities. Nearly all of those who believed in the conspiracy theories firmly believed HIV/AIDS is the United States government's attempt at genocide. Many believed conspiracy theories regarding HIV medications. Conspiracy theories about medications suggest African Americans living with HIV were only prescribed experimental HIV drugs.

*It was a governmental experiment to kill off black people. HIV was definitely created to kill us off. There's no doubt about that.*  
*(Gaynetta, 40)*

*I heard there is a cure but black people don't have that type of money.*  
*(Sandy, 45)*

*I believe they got conspiracy when it come to generic HIV medicine.*  
*Magic Johnson is getting the cure. He's tested negative. (Betty, 53)*

**HIV-related stigma.** The impact of HIV-related stigma on engagement in care and treatment adherence was one focus of the in-depth interview. Only two of the ten participants shared their perceptions of HIV-related stigma when specifically asked about the healthcare setting. One participant talked about her experience with perceived stigma when visiting the lab.

*Sometimes when I go to the lab with the younger lab techs you can tell by the looks on their faces....they know they dealing with someone with HIV. Then they claim to have trouble and ask someone else to draw the blood.*  
*(Amber, 25)*

A majority of the participants shared their experiences with HIV-related stigma that occurred outside of the healthcare setting much of which occurred within their families and social settings.

*There was a time my family used to wash the dishes with bleach and everything.* (Gail, 38)

*I had a friend who had a daughter she was like a niece to me. When she had a baby she told me I couldn't touch her baby. Man, that thing really hurt me. (Betty, 53)*

*You just can't tell some people cause they very mean. They would say "Oh bitch, that's why you got HIV". (Cathy, 58)*

**Family and social support.** The in-depth interviews also included discussions about family and social support. All of the participants spoke about this in some capacity. Nine of the participants expressed having no or very limited family and social support when it came to living with HIV/AIDS. One respondent spoke about having to place her family's needs above hers.

*My immediate family knows... they all know but like I said we don't talk about it. My problem is that I have to make sure everybody else's needs and wants are taken care of before my own. I listen to everybody else's problems but I have no one to listen to mine and it's stressful. I barely get enough sleep. I do so much for my family because I want them to feel proud of me and they just don't say anything. (Amber, 25)*

Only one of the participants spoke highly about the overwhelming love and support she received particularly from her parents.

*I've looked to my parents for support. My mother and I are very close. She has been with me through all of this. I was dealing with my marriage falling apart. I packed up me and my children's stuff and moved home to my parents' house. I'm coping better now with my diagnosis but my main focus is on my baby. She has HIV too. (Miranda, 33)*

**Religion and spirituality.** The impact faith and spirituality had on women of color living with HIV/AIDS was also discussed during the in-depth interview. Ninety percent of the participants positively expressed how their faith and spirituality have been a source of support to them. Three of the participants expressed that it was their strong faith and belief in God that had cured them therefore keeping them from consistent HIV care.

*My faith.....Ooh, that's deep because it's good. I do have the faith. I do believe that I am healed and that's one of the reasons I'm not on meds because I believe my faith is sooo strong. I believe that God is gonna heal me or that I am already healed. So that's how I'm looking at it. I've looked to Jesus for support. I've not looked to anyone on this earth for support and I don't know why that is. (Amber, 25)*

Of those positively endorsing religion and spirituality as a source of support prayer was a common theme. Prayer was commonly used as a coping mechanism as expressed by one participant...

*I prayed about it and God got me here. I pray hard. I could've been gone.*  
*(Linda, 34)*

**Abuse/violence.** During the course of the in-depth interviews several of the participants shared issues that have had a great impact on their lives. Substance abuse, childhood physical and sexual abuse, neglect, incarceration history and violence against women were intertwined into their stories of living with HIV/AIDS. Four out of 10 of the participants discussed substance abuse and how it affected their ability to stay engaged in HIV care. A respondent's statement regarding her inability to cope with living with HIV was reminiscent of others who reported substance abuse histories.

*I didn't really deal with it....it was just something that happened to me. When I couldn't deal with it I used to drink and go smoke crack. During that time I was out of care. I was using crack real bad. (Betty, 53)*

Forty percent of the participants reported having a history of enduring childhood physical and sexual abuse as well as neglect. This participant shared openly about enduring childhood sexual abuse.

*I wanted to feel safe....especially after my sexual encounter with my brother. My brother started abusing me at 8 years old. I never knew how to handle the hurt, pain, and disappointment. (Sandy, 45)*

Two of the women reported having a history of incarcerations that stemmed from acts of violence against them. Participants spoke of how their anger led to serving prison time.

*After what my brother did I would be violent towards men. If my man said something to me that I didn't like I get angry and I would fight him. I would let him know he infected me and I didn't appreciate it.*  
*(Sandy, 45)*

*I went in for aggravated assault. I was a real angry person. I spent two years in prison. (Cathy, 58)*

## Chapter 5: Discussion and Conclusion

This qualitative research explored factors impeding HIV positive women of color who reside in the urban areas of South Carolina from engaging in consistent and effective HIV care. The study explored the impact of perceived stigma in healthcare settings, family and social support, and depression on HIV care engagement. Some of the findings of this research are similar to those described in existing literature that focus on women of color living with HIV/AIDS while some points were surprisingly different. This chapter will provide a discussion of the findings and provide further analysis into the results presented in the previous chapter.

### Discussion

**HIV-related stigma.** Existing literature shows that perceived HIV-related stigma greatly impacts retention in HIV care and is associated with poor health outcomes for women of color [18, 62]. In this study only 20% of the participants reported experiencing HIV-related stigma in the healthcare setting when specifically asked. However, when participants were specifically asked about patient/provider relationships the majority shared their negative perceptions about trust and confidentiality as well as the stigmatizing attitudes and behaviors of providers. The low numbers of those who specifically identified HIV-related stigma within the healthcare setting coincide with similar findings of Wingood *et al.* who suggests women of color were more likely to attribute perceived negative experiences to race and not their HIV status [66].

In the review of the literature, patient/provider relationships and encounters greatly influence engagement in care and medication adherence. Studies have found negative attitudes of HIV care providers as barriers to engagement in care. Participants in this study described their physicians as distant, demeaning, and using condescending tones therefore

making it difficult for them to consistently engage in care but did not identify these provider behaviors as HIV-related stigma.

Current literature also shows breaches of confidentiality as stigmatizing. Participants in this study expressed concerns regarding matters of confidentiality which impacted their ability to seek care. Several of the women shared concerns about encountering healthcare employees with whom they were personally acquainted with disclosing their HIV status to others outside of the healthcare system therefore preventing them from seeking care. Charleston is a large medical center along the coast of South Carolina. There are 10 acute care hospitals in the Charleston region. Such breaches of confidentiality should be of concern considering MUSC and its entities comprise the largest healthcare system and second largest employer in the Charleston area. There is only one other smaller healthcare system providing HIV care in the area. Considering these factors those seeking HIV care in this region may have increased fears regarding breaches of confidentiality. Although few participants identified their negative experiences within the healthcare setting as stigma the majority have experienced HIV-related stigma within their family and social networks.

**Family and social support.** Ninety percent of the study participants reported having no or very little family and social support. Of those reporting having little to no family and/or social support many experienced moments of HIV-related stigma from those they looked to for support. As stated earlier in the literature review, the lack of family and social support can be harmful clinically as seen in over half of the study participants living with CDC defined AIDS. Several of the women spoke of how family members would only allow them to use paper plates and cups or not be allowed to show affection to family members' children for fear of transmission. Participants also spoke of losing family relationships and friendships once they disclosed their HIV status. The experience of HIV-related stigma and lack of support within the family and social circles caused many of the women to isolate themselves which led

to seeking solice in spirituality and religion. This research shows an inverse relationship between poor family and social support and religion and spirtituality. According to researchers, spirituality and religion impact coping skills and the overall health outcome of women living with HIV. The women affirmed the positive impact of faith and spirituality on their coping skills which is consistant with research by Dalmida *et al* [91, 93, 95, 97, 98].

Participants of this study stated it was their faith in God and prayers that would heal them from the virus therefore the need to seek HIV care did not exist to them. Although research showed religion and spirituality as positively impacting health outcomes for women living with HIV/AIDS, this was not the case for these study participants and, in fact, may have prevented them from seeking necessary care. Those with CDC defined AIDS are among participants citing their faith in God as reasons to not engage in care.

According to Peltzer, the church, a positive source of support within the African-American community, is not seen as a place where women living with HIV seek support [86]. Many of the women despite their claims of the positive impact of religion and spiritility chose to remain isolated from the church community. Only one of the participants was actively affiliated with a church community but kept her HIV status a secret for fear of being ostricized.

**Depression.** As indicated in previous research, depression among PLWHA can be linked to HIV-related stigma as well as a lack of family and social support irregardless to geographic location. Research shows prevelence rates for depression in PLWHA are higher than the overall population. The findings of this study confirm the assertion as shown in the literture review that African-American women residing in urban areas are more likely to suffer from depression and other mood disorders. The results from this study also demonstrated low numbers of participants being compliant with mental health treatment and care which is consistant with previous studies that report insufficient use of mental health services among PLWHA. Research shows women in rural areas are less likely to seek mental

health services however the results of this study could indicate the same is true for those in urban areas. PLWHA living with depression are less likely to engage in HIV care consistently as well as have lower CD4 counts with poor outcomes; the findings of this study are consistent with previous research.

### **Limitations**

This study is not without limitations. The small sample size (n=10) provided a limited number of people to explore the themes; therefore, a larger sample of women of color living with HIV/AIDS in southern urban areas who are not engaged in HIV care may provide more insight. Recall bias presents another limitation and may have played a role in participants' responses during the in-depth interviews. Participants were asked to recall times of not being engaged in HIV care and what life events were taking place at that time to impact their engagement in care. The participants average number of years living with HIV/AIDS was 8.5, which is a long period of time from which to recall specific life details. Although in-depth interviews are valuable data collection tools, they rely solely on participants to recount life events which may result in unreliable information. Another data collection limitation pertained to the use of health literacy as a measurement. In an effort to reduce the burden of completing multiple assessment tools, the use of a validated tool to measure participants' HIV knowledge and/or health literacy was not implemented. The use of such assessment tools would have provided better insight as to whether participants' lack of knowledge and understanding of HIV impacted engagement. An additional limitation to the study pertains to the data collection and analysis being solely completed by the PI. Double coding would have eliminated any biases.

## **Recommendations and Public Health Implications.**

The findings of this research study support practical recommendations for the provision of HIV care and services to women of color living with HIV in southern urban areas. A reasonable tactic to address engagement and retention issues for this population could be the provision of a “one-stop shopping” approach to HIV care. The provision of intensive case management, inclusive of on-going assessments and/or treatment of mental health issues as well as the use of Peer Navigators would be conducive to the engagement and retention efforts.

More than half of the participants in this study had documented depression diagnoses despite their CES-D scores. Implementing a trauma focused approach in the provision of HIV care to women living with HIV could be beneficial in engagement and retention efforts as well as improving health outcomes of this population. It has been noted in previous research the pervasive impact of trauma among women living with HIV [106]. A significant number of participants in this study shared their experiences with childhood abuse, sexual violence incarceration and drug abuse, all of which can be seen as traumatic life events which were not appropriately addressed.

As shown in this study’s findings and previous research many women living with HIV/AIDS have limited family and social support. Prior research indicates the development of supportive strategies such as the use of Peer Navigators to improve retention in HIV care and medication adherence. The inclusion of such strategies provide additional support to women living with HIV [41, 107]. The use of HIV positive women in the role of Peer Navigators not only provide additional social support but assist women in facilitating interactions between themselves and various parts of the healthcare system [108].

One example of the “one stop shopping” model of care is women-centered care. In addition to HIV, sexual and reproductive health care, women-centered care identifies and addresses psychosocial and support needs impacting women’s abilities to access health care. Women-centered care supports HIV positive women to achieve the best health and well-being as defined by women [109]. This model of care is flexible and driven by women's diverse experiences [110]. Ninety percent of the women in this study reported not having family and or social support. As noted in the Literature Review, the lack of support systems is stressful and harmful clinically [82]. Supportive environments, such as those providing women-centered care improve self-efficacy which reduce depressive symptoms, improve treatment adherence and ultimately improve health outcomes [64, 79, 80].

In terms of public health implications, these findings and recommendations could potentially impact the HIV Care Continuum in the areas of Engagement/Retention in Care and Viral Suppression. According to the CDC, the HIV Care Continuum is a series of steps from the time a person is diagnosed with HIV/AIDS through to the successful treatment of the virus with HIV medications [111]. Research shows that women of color experience more significant delays in the movement into and through the HIV Care Continuum [112]. Future research that focus on identifying factors that impact women of color during various areas of the HIV Care Continuum can be beneficial in developing improved HIV care and services for women of color particularly in urban areas of the Deep South.

## **Conclusions**

The study findings add to the current body of literature on HIV-related stigma in healthcare settings. These results call into question the WOC understanding of HIV-related stigma in healthcare settings. The results may also serve as a base for future studies on how the provision of HIV care from large urban healthcare systems play a role in HIV-related stigma issues such as breaches of confidentiality. The results also showed the lack of family

support caused the participants to turn to religion and spirituality. The participants strong faith proved to negatively influence their decisions to not engage in HIV care. The study also provides additional evidence with respect to the insufficient use of mental health services among women of color living with HIV/AIDS in urban areas.

Findings of this study indicate an overlapping relationship between HIV-related stigma, lack of family and social support, depression and the ability of women of color residing in urban areas of South Carolina to engage in HIV care. The perspectives of these women could lead to much needed changes within the health care system and the provision of care. The improvement of health outcomes and a reduction in the transmission of the virus could be the end result of gaining a better understanding of how these issues impact women of color living with HIV/AIDS particularly in the Deep South.

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## Appendix A

### **HIV Knowledge**

WOCNIC Study ID:

**1. Is there a cure for HIV?**

- Yes
- No
- Only by prescription
- I don't know

**2. Approximately how many people are living with HIV worldwide?**

- 34 million
- 23 million
- 13 million
- I don't know

**3. Can someone get AIDS from sharing the cup of someone with HIV?**

- Yes
- No
- Only if you don't wash the cup
- I don't know

**4. Can people get HIV from insects?**

- Yes
- No
- Only from mosquitoes
- I don't know

**5. HIV makes a person sick because....**

- It makes a person lose weight very suddenly
- It reduces the body's core temperature
- It attacks the immune system
- I don't know

6. Does HIV only affect gay people?

- Yes
- No
- Only gay men
- Only gay women
- I don't know

7. What year was AIDS first reported in the United States?

- 1975
- 1981
- 1986
- I don't know

8. It's believed that HIV developed from a similar virus found in which animal?

- Baboon
- Chimpanzee
- Elephant
- Guinea
- I don't know

9. If someone has a CD4 count of 350 or less, what does this mean?

- Their immune system is very healthy
- They no longer have HIV
- They should probably start take HIV medications
- I don't know

**Appendix B**  
**Center for Epidemiologic Studies Depression Scale (CES-D), NIMH**

WOCNIC Study ID: \_\_\_\_\_

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**Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way DURING THE PAST WEEK.**

1. I was bothered by things that don't usually bother than 1 day) me. days)	<input type="checkbox"/>	Rarely or none of the time (less
	<input type="checkbox"/>	Some or a little of the time (1-2
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	Rarely or none of the time (less than 1
	<input type="checkbox"/>	Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
3. I felt that I could not shake off the blues even than 1 with the help of my family or friends. days)	<input type="checkbox"/>	Rarely or none of the time (less
	<input type="checkbox"/>	Some or a little of the time (1-2
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
4. I felt that I was just as good as other people.	<input type="checkbox"/>	Rarely or none of the time (less than 1
	<input type="checkbox"/>	Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	Rarely or none of the time (less than 1
	<input type="checkbox"/>	Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
6. I felt depressed.	<input type="checkbox"/>	Rarely or none of the time (less than 1
	<input type="checkbox"/>	Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)

7. I felt everything I did was an effort.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
8. I felt hopeful about the future.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
9. I thought my life had been a failure.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
10. I felt fearful.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
11. My sleep was restless.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
12. I was happy.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
13. I talked less than usual.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
14. I felt lonely.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days) Occasionally or a moderate amount of the time (3-4 days) Most or all of the time (5-7 days)
15. People were unfriendly.	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days)

		Occasionally or a moderate amount of the time (3-4 days)
		Most or all of the time (5-7 days)
16. I enjoyed life.	<input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
17. I had crying spells.	<input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
18. I felt sad.	<input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
19. I felt that people disliked me.	<input type="checkbox"/>	Rarely or none of the time (less than 1 day) Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)
20. I could not get "going".	<input type="checkbox"/>	Rarely or none of the time (less than 1 day)
	<input type="checkbox"/>	Some or a little of the time (1-2 days)
	<input type="checkbox"/>	Occasionally or a moderate amount of the time (3-4 days)
	<input type="checkbox"/>	Most or all of the time (5-7 days)

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**SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.**

Score: \_\_\_\_\_

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Radloff LS. 1977. The CES-D scale: a self-report depression scale for research in the general population. Applied Psychological Measurement 1:385-401

Center for Epidemiologic Studies Depression Scale. Developed by National Institute of Mental Health. Available from NIMH, 6001 Executive Boulevard, Room 8184, MSC 9663, Bethesda, MD 20892-9663; phone: 301-443-4513. Website: <http://www.nimh.nih.gov>

## Appendix C

### South Carolina Women of Color Not in Care Interview Guide

**P1.** *WOCNIC ID No:* \_\_\_\_\_

**P2.** *Interviewer ID:* paytonharmon

**P3.** *Interview date:*         /    /                  

**P4.** *Time interview began:*   :   **AM↑PM**

**SAY:** "I'd like to thank you for taking part in this interview. I want to ask you some questions and I want you to describe your thoughts and experiences. I'd like to start by asking you to tell me about yourself. The first three questions will be used to develop a unique identifier for you. This will help protect your identity and confidentiality. Remember that all the information you give me will be private and your name will **not** be recorded anywhere. When we are ready to start, I'll turn on a tape recorder to record us while we talk. Do you have any questions? [PAUSE FOR QUESTIONS] I'd like to start the tape recorder now."

**I. The Participant**

1. Would you please tell me how old you are?
2. What is your month and date of birth?
3. Please tell me the last four digits of your cell phone number.
4. What is your race?
5. Do you consider yourself to be Hispanic?
6. What city do you currently reside in?
7. What is your zip code?
8. Do you live in a house, apartment, mobile home or shelter?
9. What's your relationship status?
10. Do you have any children?
  - a) If yes, how many and what are their gender and ages?
  - b) If yes, do they live in the same home with you?
11. Are you currently pregnant?
  - a) If so, how many months are you?
12. Are you currently the caregiver for anyone? For example, elderly; PLWHA; or anyone else with an illness or disability?
  - a) If so, how many of these people live with you?
13. What is the highest grade you completed in school?

**WOCNIC ID No:** \_\_\_\_\_

14. What is your total monthly household income?

- a) Employment income \$\_\_\_\_\_
- b) Disability/SSI \$\_\_\_\_\_
- c) Child support \$\_\_\_\_\_
- d) Family Independence \$\_\_\_\_\_
- e) Other \$\_\_\_\_\_
- f) **TOTAL:** \$\_\_\_\_\_ (enter with decimal point)

15. What kind of health insurance do you have?

## **II. Living with HIV/AIDS**

I would like to ask you about your experiences living with HIV.

1. Do you recall what year it was when you were first diagnosed with HIV?
2. What was the reason you decided to get tested?
3. How did you feel when you first learned you were HIV positive and in what ways did you deal with your feelings?
4. Tell me what was going on in your life and with your family at the time you were diagnosed...
5. How do you feel now about being HIV positive?
6. How does your faith or spiritual beliefs help you with your HIV status?
7. Who or who else have you looked to for support since being diagnosed with HIV and why?
8. How soon after being diagnosed did you see a medical provider for HIV medical care?
  - a) If never, tell me what was going on in your life and family that may have caused you not seek medical care.
  - b) If you have ever gone to an HIV medical appointment tell me what has been your overall experience with the doctor/nurse and the clinic staff?
  - c) Since seeking care have you ever gone 12 months or more without seeing HIV medical provider? If so, tell me what was going on in your life and family during the time you stopped going for HIV medical care.
9. Of the things that were going on in your life at the time of your diagnosis what do you feel were the main reasons for not seeking HIV care? **OR** Of the things that were going on in your life at the time when you dropped out of care what do you feel were the main reasons for not remaining in care?

### **III. Health Care Utilization History (HCUH)**

I'd like to hear about your past healthcare experiences.

- 1.Think about your health care experiences in the 5 years **before** you learned of your HIV status. Please tell me about any problems that kept you from getting medical care when you needed it.
- 2.Thinking back to your **past medical care prior to your HIV diagnosis**.... please share, if any, negative experiences you've endured prior to learning of your HIV diagnosis.
- 3.Thinking back to your **past medical care prior to your HIV diagnosis**.... please share, if any, positive experiences you've had prior to learning of your HIV diagnosis.
- 4.Do you have a preference for alternative/holistic treatments, such as herbal and vitamin supplements; following a certain type of diet; acupuncture; or yoga?
  - a) If so, what alternatives/holistic treatments have you tried?
  - b) Why do you prefer alternatives/holistic treatments?
- 5.Have you ever been told by a medical professional that you suffer from depression?
  - a) If yes, were you told this before or after you learned about your HIV diagnosis?
  - b) If yes, did you ever see a mental health professional?
    - i. If not, what are the reasons for you not seeing a mental health professional?
    - ii. If yes, were you ever prescribed medications to treat your depression? If you were, did you take the medication that was prescribed? If not, why not?

### **IV. Illness Perception and Stigma (IPS)**

1. Are/were you afraid others would find out your status?
2. Are/were you afraid that your family or significant other would be angry with you for being HIV positive?
3. Are/were you afraid the Department of Social Services (DSS) will take your children away from you?
4. How do you feel the person/medical provider who informed you of your HIV status treated you?

5. What level of trust do you have in the healthcare system when it comes to your HIV diagnosis and HIV care?
6. What has been your experience with stigma and receiving HIV healthcare?
7. Are/were you afraid about the doctors asking questions about your sexual behaviors?
8. Are/were you afraid of being asked about any illegal drug use?
9. Since there is no cure for HIV do you believe there isn't a need to take HIV medication?
  - a) If you believe there is no need to take HIV medication what are your reasons for feeling this way?
10. Do you believe there is any truth to the idea that HIV is a governmental conspiracy to kill people of color?

#### **V. HIV Resource Knowledge**

1. Did you have any problems finding a healthcare provider for your HIV care?
  - a) Did you have any problems getting an appointment for HIV care? If so, what kind of problems did you experience?
  - b) Did you have any problems getting an appointment that worked with your schedule
2. Were you worried about being able to pay for your HIV care and medications?
3. An AIDS Service Organization (ASO) is a service organization that is community based and its primary function is to provide needed services to individuals infected with HIV. They provide support services for the families and friends of those living with HIV/AIDS as well as conduct prevention efforts. Are you familiar with any ASOs within our community?
  - a) If so, can you name any of those local agencies?
  - b) If so, can you name some of the services the local ASO provides?
4. Did you know if you were unable to afford your HIV medications there is funding available to provide your HIV medication at no cost to you?
5. Did you know there is funding available to provide persons with HIV housing assistance?

**WOCNIC ID No:** \_\_\_\_\_

**SAY:** "That was the last question. We are now finished with the interview. Thank you for making time to talk with me. Just as a reminder, everything you told me will be kept private. Do you have any questions about HIV, HIV care, or anything that we have talked about today?"  
**[PAUSE FOR QUESTIONS]**

**P1.** **WOCNIC ID No:** \_\_\_\_\_

**P2.** **Interviewer ID:** paytonharmon

**P3.** **Interview date:**            /       /           
M   M   D   D   Y   Y   Y   Y

**P4.** **Time interview ended:**   :   **AM↑PM**

**P5.** **Interview transcribed:**       /       /           
M   M   D   D   Y   Y   Y   Y

**P6.** **Data entered for analysis:**       /       /        
M   M   D   D   Y   Y   Y   Y

## **Observation Form for the Qualitative Interview**

**OF1a.** Record your observations of the interview setting. This may include information such as a description of the interview location (privacy, security, etc):

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**OF1b.** Describe any external interruptions during the interview:

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**OF2a.** Record your observations and perceptions of the respondent. This may include information about the respondent's behavior during the interview:

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**OF2b.** Describe the participant's cooperation in answering the questions:

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**OF2c.** Describe the participant's comprehension of the questions:

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**WOCNIC ID No:** \_\_\_\_\_

**OF2d.** Describe the participant's mental and physical state:

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**OF3a.** Record your observations about the respondent's rapport with the interviewer. This may include whether the respondent was engaged or distant during the interview.

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**OF4.** How confident are you of the validity of the respondent's answers?

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