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EVALUATION OF A CLINIC-BASED PEER NAVIGATION PROGRAM (PNP) FOR AFRICAN AMERICANS LIVING WITH HIV IN SOUTH CAROLINA

by

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DEDICATION

“Remember who you are. [Ben and Abby] bore a whip and picked cotton so you could be here. You are the one. You are the survivor of those who were able to survive. You were born [to Abraham and Della] with the privileges of strength, resilience and perseverance. You are [Julia Ann’s] heir and [she] paid a big debt just for you. Don’t put that in jeopardy.”

Adapted from Iyanla Vanzant

This dissertation is dedicated to my Uncle Arthur Lee and my Aunt Bee. May your spirits continue to brighten our paths and bring laughter to our aching souls.

ACKNOWLEDGEMENTS

This has been an extended process peppered with highlights and hurdles that required an omnipotent force. All thanks and honor for the strength of God. I would also like to thank my husband, Trey Willis; my parents, Abraham and Della Butler; my sisters – The Butler Girls, Karen, Stacia, and April; and my entire village for their unwavering support over these very complicated and unpredictable years. I am so blessed to have a strong, unconditional, supportive, fun and wildly inappropriate family that lifts me up while keeping me grounded. It will forever be my goal to make you proud. I would also like to thank my committee chair, Dr. Alyssa Robillard. She has the patience of a saint with a keen ability to constructively critique with genuine compassion. This journey together has fostered a friendship that I needed to make it through successfully. Thank you to my committee members. You have known me for over 10 years and watched me grow personally and professionally. I expect to continue our work together. Lastly, special thanks to my coworkers for your assistance through this process, and your hard work and dedication to the care of our patients. This is just the beginning.

ABSTRACT

Peer navigation programs have been identified as a potential motivator in care engagement and retention for patients living with HIV, although the data is inconsistent. HIV management requires important disease management considerations and innovative approaches for patient care. Medication advancements and technology have drastically improved care for most patients living with this chronic disease; yet African Americans contract, live with, and die because of HIV-related complications at disproportionately higher rates compared to their White peers.

The purpose of this exploratory mixed-methods outcome evaluation is to: (1) determine if peer navigation is a viable intervention to improve three key HIV care metrics: viral suppression, care engagement and care retention; and (2) better understand factors associate with PNP that encourage and discourage participation for African American patients living with HIV at the Palmetto State HIV Center in South Carolina from January 1, 2016 to December 31, 2018.

Of the Palmetto State HIV Center's 972 HIV patients, 64.8% (n=630) were African American; and 24.4% (n=154) were enrolled in the PNP. A stepwise process resulted in 96 African American patients being included in this exploratory matched case-control quantitative evaluation. Forty-eight (48) PNP patients were randomly matched with 48 Non-PNP patients controlling for gender, age, initial CD4 count, and self-reported HIV risk factor. Additionally, fifteen African American adults living with HIV and receiving care at a clinic in South Carolina were interviewed to better understand the patients’ perception of a Peer Navigation Program (PNP) and to identify key factors that encourage or discourage participation.

Results suggested one positive outcome and a few complimentary program strengths. There was a significant change in the proportion of PNP patients that were virally suppressed after engagement in the PNP. When considered alongside responses from the patient interviews, there were several components from the PNP that promoted medication adherence to include authentic connections with their providers, extended appointment times, and high-quality comprehensive care. There was no significant difference in engagement or retention within the PNP group or between the PNP and Non-PNP groups.

Peer navigation is an intervention in HIV care and has the potential to be a promising service for the patients of the Palmetto State HIV Center. A process evaluation is recommended to fully understand the nuances of the full-service delivery, from patient recruitment to facilitation to patient discharge. A multidisciplinary team of administrators and evaluators should work collaboratively with the Peer Navigation and behavioral health team to fully understand patient needs and how they coincide with the purpose of the PNP.

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CHAPTER 1

INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), a chronic disease is a condition that lasts a year or more and requires continuous medical care and/or limits daily functions (CDC, 2019). Chronic diseases have become the leading causes of death and disability, contributing to over $3 trillion in annual healthcare expenses. Six in ten adults in the United States are living with a chronic disease, and four in 10 have two or more (CDC, 2019). Compared to their White counterparts, African Americans and adults from the Southern region of the United States are more likely to be diagnosed with and die prematurely due to the most prevalent and well-known chronic diseases: heart disease, cancer, and stroke (CDC, 2017). Other diseases traditionally considered infectious have also come to be accepted as chronic and mirror ethnic and regional health disparities, namely Human Immunodeficiency Virus (HIV).

In 1989 during an international HIV meeting in Quebec, the Director of the National Cancer Institute declared that “AIDS was a chronic illness and that treatment should follow the model of cancer.” As illustrated in this statement, the widespread use of HIV medication, or antiretroviral therapy (ART), has shifted the perception and treatment protocols of HIV and how the disease is clinically managed by providers and patients (Fee & Fox, 1992). When taken as prescribed, ART improved the overall health for the patient, reduced transmission risks, and increased life expectancy (Deeks et. al, 2013).

The transition of HIV from a fatal disease to a chronic condition requires important disease management considerations and innovative approaches for patient care. Access to routine medical care for chronic disease patients can be challenging and is often coupled with a list of environmental and psychosocial determinants that can exacerbate disease outcomes (McBrien et al, 2018). HIV patients have cited lack of insurance, cost of care, organization and delivery of healthcare, and transportation as significant barriers to accessing care and treatment (Dombrowski et al, 2015; Yehia et al, 2015). HIV also carries a burden of shame and stigma that are counterproductive to effective and sustained treatment (Hutchinson & Dhairyawan, 2018).

Comparable to other chronic diseases, there are significant racial and regional disparities in HIV diagnoses and HIV-related deaths. Despite medication advancements and technology, African Americans contract, live with, and die because of HIV-related complications at disparate rates compared to their White peers. In 2017, 43% of people diagnosed with HIV in the United States were African American, despite the fact that African Americans only represent 13% of the US population (CDC, 2019; US Census Bureau, 2019). This has been a steady trend since the onset of the disease, and is particularly evident in the Deep South region of the nation. The Deep South (AL, FL, GA, LA, MS, NC, SC, TN, TX) has the highest HIV diagnosis rate of any other US region (Reif, Belden, Wilcon & McAllaster, 2019). According to the Southern HIV/AIDS Strategy Initiative, African Americans living with HIV in the Deep South account for 53% of HIV diagnoses in the region (Reif, Belden, Wilcon & McAllaster, 2019).

One of these Deep South states – South Caorlina (SC) – ranks eighth in the nation for people living with diagnosed HIV infection (CDC, 2019). The SC Department of

Health and Environmental Control (SC DHEC) estimates that 63% of people living with HIV in SC are African American (2018), and majority are African American men (See Figure 1). Despite substantive prevention and treatment efforts, , the total number of those living with HIV/AIDS in the SC continues to rise (SC DHEC, 2018). Since 2008, the number of African Americans living with HIV in SC has been at least 200% higher than their White counterparts; 2017 marked the first time the difference between African Americans and White HIV cases fell under 200% in a decade at 167% (SC DHEC, 2018; See Figure 2).

SC DHEC estimates that 20% of those living with HIV are unaware of their status, and an even greater number are aware of their status but do not access care. Thirty-six percent of people with a known positive HIV status are not in care in SC (Edun, Iyer, Albrecht, Weissman, 2017). While the race of those who are not in care in SC is unknown, the CDC reports that at the national level, African Americans account for the largest group of people who are out of care and are virally unsuppressed (CDC, 2019). Moreover, African Americans are more likely to be lost to care, more likely to present with late-stage disease, and are less likely to reach viral suppression than patients of other races (CDC, 2019). This highlights HIV as a long-standing, chronic health disparity for African Americans in SC and emphasizes the need for effective strategies to promote HIV care and treatment.

Researchers and practitioners have explored concepts of patient navigation as a viable healthcare strategy for people living with HIV (Gardner et al, 2005). Patient navigation was developed in 1990 to address factors that impact healthcare seeking behaviors of poor Americans living with cancer, like cost (monetary and social), fatalism, traumatic healthcare experiences, and the lack of cultural sensitivity (Freeman, 2012).

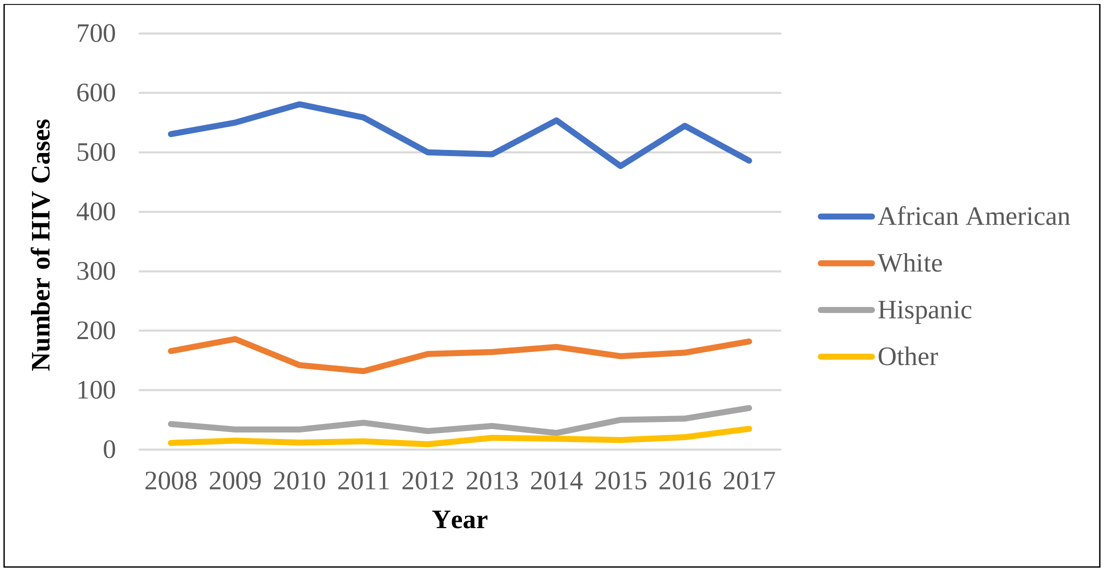

Figure 1.1. Number of SC HIV Cases by Race and Year of Diagnosis

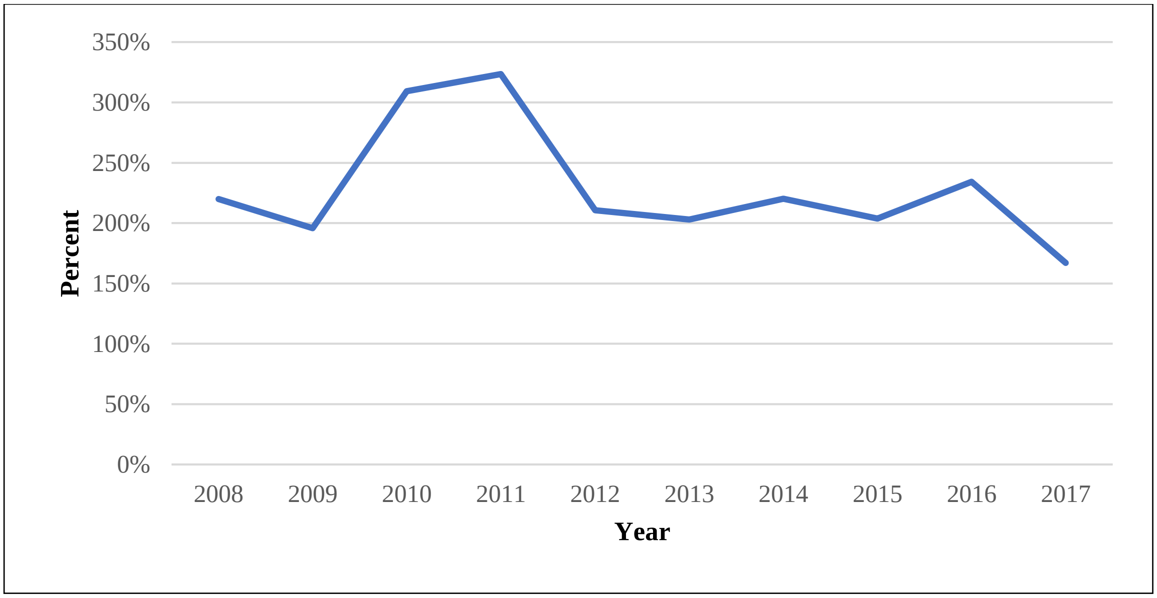

Figure 1.2. Percent Difference between African American and White HIV Cases in SC

These barriers to healthcare seeking behavior were used by Freeman (2012) as he designed and defined a newfound strategy of patient navigation that could be used to improve health outcomes for vulnerable populations. Nearly 30 years later, patient navigation continues to be a viable healthcare strategy for chronic disease management that can be applied to HIV disease management (Gerves-Pinquie et al, 2018; Kelly et al, 2015).

While research has shown that patient navigation programs for people living with chronic diseases can significantly enhance care processes and outcomes, results have been inconsistent in terms of whether these programs are effective at increasing patient retention and viral suppression for people living with HIV (Kelly et al, 2015; Mizuno et al, 2018). The primary purpose of the proposed study is to evaluate the impact of the Peer Navigation Program (PNP) of the Palmetto State HIV Center, a sexual health center in SC, using patient engagement (PE), care retention (CR) and viral suppression (VS) among African American adult patients. In addition, this study will explore the contextual (i.e., organizational) factors that influence program participation.

The PNP will be evaluated using a convergent triangulation mixed methods design with two concurrent data collection and analyses phases: 1) a retrospective, cross-sectional and case-cohort analysis using data extracted from medical records, and 2) a qualitative analysis of the contextual factors that influence participation in the PNP. Data collected from African American adults enrolled in the PNP from January 2016 to January 2018 will be examined to (1) compare outcomes before and after PNP participation, and (2) compare to African American adults who were patients of the Palmetto State HIV Center during the same timeframe but never participated in the PNP. Qualitative methods will be also used to explore contextual factors that influence program participation. Quantitative data will include a review of patient medical records to gather HIV biological and care metrics, and qualitative data will include patient, peer navigator and clinic administrator interviews to understand the context of PNP delivery.

1.1 SPECIFIC AIMS

The specific aims (and related hypotheses/research questions) for this study are:

SA1. To determine the effectiveness of a Peer Navigation Program (PNP) for African American adults living with HIV using the following objective and biological HIV care metrics: patient engagement, care retention, viral load, and achievement of viral suppression;

> **H1.** African American PNP participants will have a higher patient engagement rate, higher care retention rate, and lower viral load after PNP participation compared to levels at baseline. A greater proportion of African American PNP participants will achieve viral suppression after PNP participation compared to levels at baseline.
>
> **H2.** African American PNP participants will have a higher patient engagement rate, higher care retention rate, and lower viral load after PNP participation compared to African American patients who did not participate in the PNP. A greater proportion of African American PNP patients will achieve viral suppression after PNP participation compared to African American patients who did not participate in the PNP.

SA2. To qualitatively assess what factors are associated with PNP participation among African American adults living with HIV.

> **RQ1.** What are patients’ perceptions of the PNP?
>
> **RQ2.** What factors encourage patient participation in the PNP?

RQ3. What factors discourage patient participation in the PNP?

CHAPTER 2

BACKGROUND

2.1 HUMAN IMMUNODEFICIENCY VIRUS (HIV)

HIV is a progressive virus that is transmitted through four bodily fluids: vaginal secretion, semen, breast milk, and blood. Upon acquisition, the disease attacks the body's CD4 cells (also known as T cells) making it harder to ward off infections and other diseases (US DHHS, 2019). This deterioration can occur for many years without significant or apparent signs or symptoms, also known as phase two or clinical latency. AIDS is the tertiary phase of the disease and is often the most severe. The immune system has been depleted allowing the onset of critical illnesses called opportunistic infections (US DHHS, 2019).

Antiretroviral medication has been approved to treat HIV since March 19, 1987 (USFDA, 2018). Although treatment was available, unfettered access was not available until 1996 with the inception of the US AIDS Drug Assistance Program (ADAP), resulting in a great decline of AIDS deaths over the decades (Meissner, 2018). In spite of this, there was still a significant and consistent racial disparity among AIDS deaths. In 2000, the CDC standardized the definition for AIDS to allow equitable comparisons across years (CDC, 2001). In that year, 58% (n = 448,060) of people living with AIDS in the United States died due to AIDS-related complications. Of these deaths, 61% were African American or Hispanic (CDC, 2001). In 2016, only 2% (n = 525,374) of people living with AIDS died; yet still, 61% were African American or Hispanic (CDC, 2019).

Medication adherence is essential to achieve viral suppression, increase life expectancy, and prevent HIV (Meissner, 2018). Medical researchers have discovered ways to simplify the HIV treatment regimen by combining drugs into small, single-dose tablets. In 1987, azidothymidine (AZT) was the only FDA-approved drug that effectively prevented the HIV virus from replicating. It was exorbitantly expensive ($17,000 to $25,000 annually) and caused a litany of serious side effects (USFDA, 2018). By 2000, combination therapies were introduced called highly active antiretroviral therapy (HAART). These medication cocktails combined HIV drugs from six different classes: entry inhibitors, fusion inhibitors, nucleotide/nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, integrase inhibitors, and protease inhibitors (USFDA, 2018). Each class plays a specific role in the destruction of the HIV virus; and the best combination of the classes is determined by a trained medical provider. The evolution of HIV medication has created cleaner, safer drugs, yet access to the drugs and prescribing provider still serves as a barrier for African American patients, thus widening health disparities.

2.2 HIV DISPARITIES

Health disparities are defined by the CDC as “differences in the incidence, prevalence, and mortality of a disease and the related adverse health conditions that exist among specific population groups” (2019, p.1). Despite medical advancements and technology, African Americans contract, live with, and die because of HIV-related complications at disparate rates compared to their White peers. In 2017, 38,739 people were newly diagnosed with HIV; 43% (n=16,694) were African American. Moreover, the CDC estimates an additional 16% are unaware of their status (CDC, 2018). African

Americans comprise only 13% of the United States population, yet account for 42% of people living with HIV infection or HIV infection ever classified as AIDS (CDC, 2018; US Census Bureau, 2019). This (racial/ethnic) disparity has been observed since very early in the course of the epidemic.

Notably, African American women, youth (ages 13-24), and men that have sex with men (MSM) have been especially impacted by the HIV epidemic. Among all women, African American women account for the largest percentage of new HIV diagnoses with an HIV acquisition rate that is 15 times higher than that of White women and almost five times higher than Latina women (Kaiser Family Foundation, 2019). African American youth, namely young MSM, account for 54% of new HIV diagnoses within their age group. According to the CDC, MSM adult and youth represent 58% of new HIV diagnoses among African Americans, and most (79%) are newly diagnosed (CDC, 2018).

Geographically, African Americans in the Southern region carry the greatest burden of HIV. The southeastern region of the United States (AL, FL, GA, LA, MS, NC, SC, TN, TX), also known as the Deep South, has the highest rate and number of people diagnosed with HIV and AIDS of any other US region, and African Americans are disproportionately impacted (Reif, et al, 2019). According to the Southern HIV/AIDS Strategy Initiative, African Americans living with HIV in the Deep South account for 53% of HIV diagnoses in the region (Reif, et al, 2019). SC has the sixth highest incidence rate and fourth highest prevalence rate of the aforementioned Southern states (CDC, 2018). HIV rates for African American men and women in SC are nearly six times and 18 times higher compared to White men and women, respectively (CDC, 2018; See Figure 3).

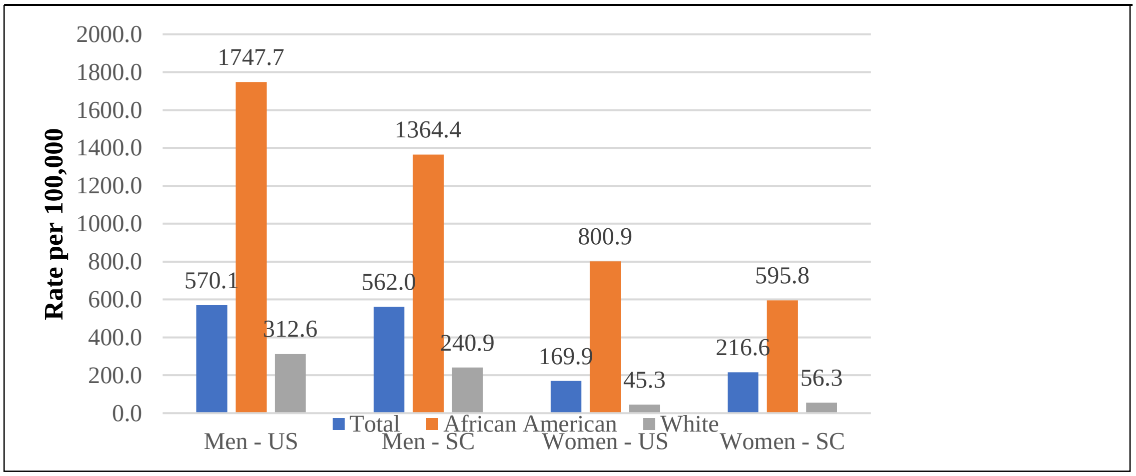

Figure 2.1. US and SC HIV Rates by Race and Sex, 2017

In 2013 by Executive Order of the President, the HIV Treatment Continuum was created to establish national goals for HIV care (Office of National AIDS Policy, 2013). The four steps – diagnosis, linkage to care, retention in care, and viral suppression – are often bidirectional for patients, but viewed as a linear cascade for health professionals to gauge progress for a population of people (Kay, Batey, & Mugavero, 2016). The CDC provides two distinct continua of care to include and exclude undiagnosed HIV infection. It is estimated that 86% of people with HIV have been diagnosed. When undiagnosed HIV is included (prevalence-based), 64% of people living with HIV are linked to care, 49% are retained in care, and 53% are virally suppressed. When undiagnosed HIV is excluded (diagnosis-based), there is a slight increase in outcomes. Seventy-four percent of people living with diagnosed HIV are linked to care, 58% are retained in care, and 62% are virally suppressed (CDC, 2019). In SC, percentages are about 5% lower than national percentages that exclude undiagnosed HIV (SC DHEC, 2019; See Figure 4).

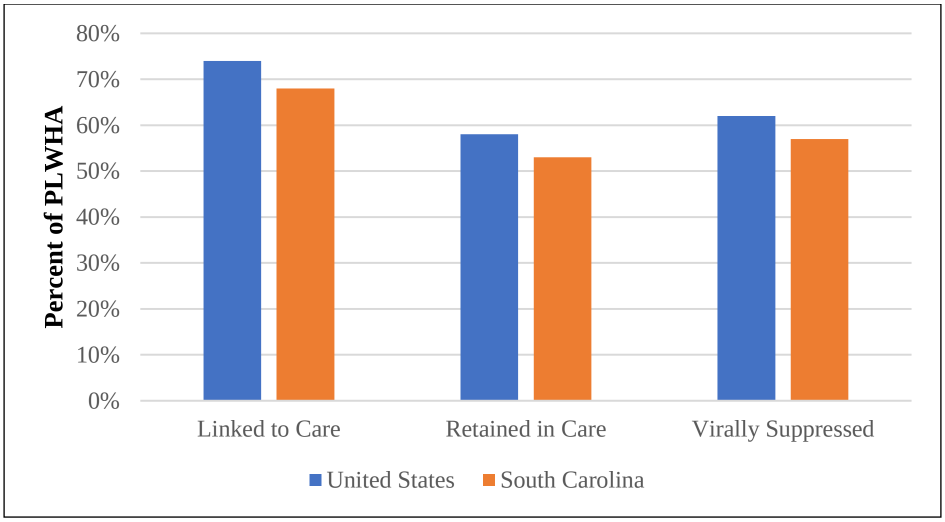

Figure 2.2. Diagnosis-Based HIV Care Continuum, 2017

These numbers are far from the newest international 90-90-90 treatment initiative: by 2020, 90% of people living with HIV will know their status, 90% of people living with HIV will receive sustained ART, and 90% of people on ART will be virally suppressed (UNAIDS, 2014). Nationally, the goals are slightly lower. By 2020, the National HIV/AIDS Strategy purports that 90% of people living with HIV will know their status, 85% of people will be linked to care, and 80% of people living with HIV will be virally suppressed (CDC, 2019). Yet still, without intervention to reduce disparities, African Americans will once again be struggling to meet these goals.

Like HIV diagnosis rates, there are also significant disparities in care linkage, care retention and viral suppression for African American patients. However, research shows that African Americans do not engage in riskier behavior than other racial groups and urges researchers to extend beyond individual behaviors to investigate differences in healthcare outcomes (Millett, Flores, Peterson, Bakeman, 2007).

2.3 THEORETICAL PERSPECTIVE ON HIV RISK AND IMPACT OF CARE AND TREATMENT IN THE SOUTH

A socioecological view of the most pervasive HIV risk factors connected with the Deep South could be used to better understand the region's unique and shared challenges. The Modified Social Ecological Model posed by Baral, Logie, Grosso, Wirtz, and Beyrer (2013) provides an alternative to the standard Social Ecological Model and is specific to HIV. The standard theory considers relationships within, between and independent of factors across all levels of a health problem. The levels of influence include: (1) Intrapersonal/Individual Factors, (2) Interpersonal Factors, (3) Institutional and Organizational Factors, (4) Community Factors, and (5) Public Policy Factors (Glanz, 1997). Like the Social Ecological Model, the modified version also consists of five levels: (1) Individual Level, (2) Social and Sexual Networks, (3) Community, (4) Public Policy, and (5) HIV Epidemic Stage (Baral et al, 2013; See Figure 5). Stages one through four are comparable to the traditional model, but the modified model combines institutional and community factors and adds the HIV epidemic as a level to conceptualize the influence of population health on individual behaviors. In addition, this model explains that levels are permeable hence factors can be reflected within multiple levels (See Table 1). Together, these factors give context to the complex and multi-dimensional nature of health problems and interventions.

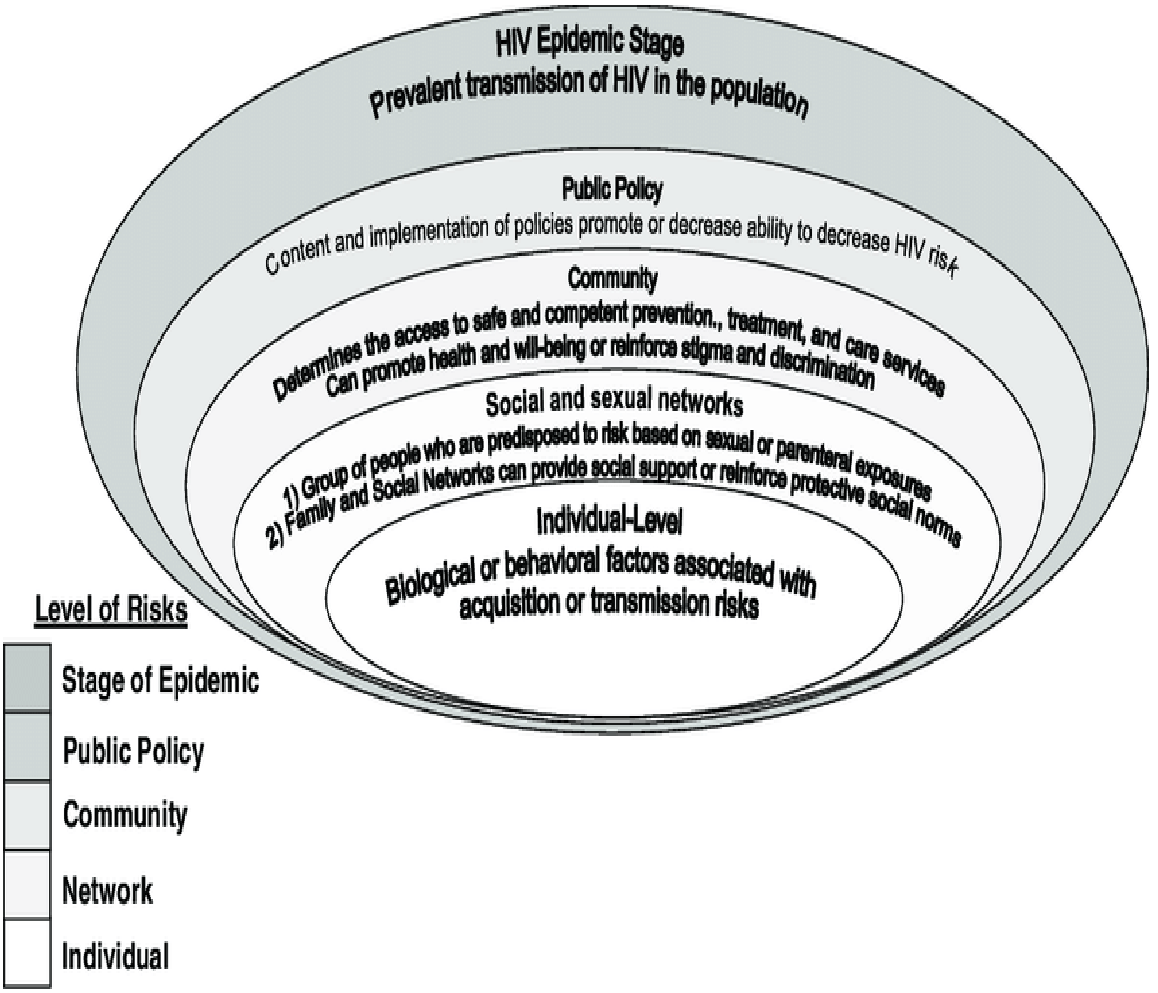

Figure 2.3. Modified Social Ecological Model

Individual factors are characteristics that influence behavior, like knowledge, attitude, beliefs and skills. Yakob and Ncama (2016) correlate individual knowledge and/or experience with HIV care and treatment as a precursor to one's own engagement in HIV care. Patients that knew of someone that benefited from HIV treatment or witnessed someone die because of no HIV treatment were more inclined to engage and comply with their own HIV treatment plan (Yakob & Ncama, 2016).

Moreover, patients believe that HIV care and treatment are secondary to other necessities like food, shelter, and clothing (Baral, Logie, Grosso, Wirtz & Beyrer, 2013).

Table 2.1. Modified Social Ecological Model of HIV Care and Treatment Factors in the Deep South

Social Ecological Model (SEM)	Modified Social Ecological Model (MSEM)	Definition of MSEM Level	Associated Factors in the Deep South
Intrapersonal	Individual	Biological or behavioral factors associated with HIV care and treatment	Knowledge Attitude Beliefs Social Determinants of Health HIV Disclosure Stigma Shame
Interpersonal	Social & Sexual Networks	Group of people who are predisposed to insufficient HIV care and treatment, and their social networks that support or discourage care	HIV Disclosure Stigma Shame Race Concordant Dating
Institutional	n/a		
Community	Community	Access to safe, high quality HIV care and treatment, and systems that support or discourage care	Social Determinants of Health Poverty Homophobia Stigma Medical Mistreatment Implicit Bias Ryan White Care Act
Public Policy	Public Policy	Policies and laws that support or discourage HIV care and treatment	Homophobia Stigma Medicaid Expansion Ryan White Care Act
n/a	HIV Epidemic Stage	Prevalence and incidence of HIV with the population	HIV Rates in SC STI Rates in SC

Patients may forgo treatment to allow more time and resources to regain and secure these basic needs. This is an example of a transferable factor, in that it exists in multiple levels. Social determinants of health, or the conditions in the places where we live, work, and play, are both individual- and community-level factors that can be influenced and should be considered by HIV healthcare centers (CDC, 2019). To respond to this need, healthcare centers can refer patients to or provide in-house supplemental social services, like a food pantry, workforce development, or transportation.

According to Baral, et al. (2013), social network factors can include groups of people who are predisposed to risk because of sexual or perinatal exposures as well as family and social networks that offer social support or reinforce protective social norms. Other transferable factors are the ability to disclose one’s HIV status, stigma, and shame. As both a social network and individual factor, HIV disclosure is a learned skill. People living with HIV who do not disclose their HIV status are less likely to be medically compliant with their HIV care (Mi et al, 2019). This is commonly rooted in stigma and shame associated with HIV acquisition. Internalized and externalized stigma and shame have been cited as pervasive barriers to HIV testing and care in the Deep South (Reif et al, 2011). The region’s conservativism influences HIV stigma among people living with the disease, thereby discouraging behaviors like HIV care and treatment (Rueda et al, 2016; Human Rights Watch, 2011).

Social and sexual networks consider interactions between the individual and other people in his/her/their networks (i.e., family, friends) that may provide social support or create barriers for a specific behavior. Again, Southern conservatism impedes communication about HIV/STI care and treatment between and within social networks.

In addition to the aforementioned factors, researchers have introduced the limited pool of sexual partners as an additional antecedent of high HIV rates. According to the US Bureau of Justice Statistics (2019), six of the 10 Deep South states have incarceration rates higher than the national rate and are within the top 15 imprisonment rates in the country. Mass incarceration of Black men and race-concordant dating preferences limit the pool of African American sexual partners, thus incubating and circulating sexually transmitted infections (Wohl, 2016). Thereby, sexually transmitted infections like HIV are left unattended and are transmitted, knowingly and unknowingly, between sexual partners. For populations at heightened risk, treatment as prevention (TasP)—the use of antiretrovirals to attain/maintain viral suppression to prevent the sexual transmission of HIV (HIV.gov, 2019), is critical for care and for stemming transmission. Hence, a limited pool of partners at heightened risk that do not know their HIV status and are not linked to care pose a risk for contracting and transmitting the virus. This factor is also observed in the HIV epidemic stage as well.

Community factors are the larger, organizational networks, processes, culture and standards that support or discourage behavior. Poverty, racism, medical mistreatment, and again, stigma coupled with religious-based homophobia are community level factors that affect opportunities for HIV care and treatment. Poverty within the Southern African American community has been correlated with poor health outcomes and high STI prevalence (Ahnquist, Wamala, & Lindstrom, 22; Pellowski, Kalichman, Matthews & Adler, 2013). Southern states have the highest unemployment rates, lowest median income, and highest uninsured rates (Heiman & Artiga, 2016; Napravnik, Eron &

McKaig, 2007). Poor communities lack resources and medical access promoting the spread of disease.

Generational poverty for Southern African Americans is a consequence of decades of limited access to employment, transportation, housing, and education due to laws enacted during slavery and later during the eras of the Black Codes and Jim Crow (History, 2019). Lack of access to these essential social determinants of health compounds the problem resulting in African Americans consistently experiencing poorer health outcomes compared to their White counterparts (Bailey et al, 2017).

More specifically, the Deep South is known for its healthcare deficits and inequities for African Americans as a result of sustained individual and institutional racism (Bailey et al, 2017). Racism in medicine has a long, engrained history in the American South. From biological fallacies, myths, and mistreatment of enslaved Africans during the Middle Passage to medical experimentation of slave women by J. Marion Sims in SC to the clinical trials of Syphilis in Tuskegee, Alabama, African Americans have historically received unjust treatment and inequitable healthcare in the South by healthcare providers and the systems in which they work (Southern Poverty Law Center, 2019). Thus, generational stories of medical mistrust and mistreatment deter African Americans from seeking essential HIV care or dilutes the trust needed to adhere to a prescribed HIV care regimen. Even recent studies confirm that centuries-old racial misconceptions still influence present-day care and healthcare outcomes for African Americans. Hoffman et al (2016) found that a significant amount of the medical providers (laypeople, medical students, and residents) held false beliefs about the biological differences between Whites and Blacks, like “Blacks’ nerve endings are less sensitive than Whites." and "Whites have a better sense of hearing compared with Blacks." Moreover, those that endorsed these beliefs rated the pain of Black patients lower than their White counterparts even when presented with the same ailments.

Public policy factors include content and implementation of policies that promote or decrease HIV risk (Baral, et al., 2013). Stigma is a consistent thread across all levels of the model that is exacerbated by religious-based homophobia. Homophobia in SC is reflected within the public policy level of the MSEM in that it has been embedded within policies impacting sexual health education. According to a survey conducted by the Pew Research Center (2014), 42% of adults in SC report that homosexuality should be discouraged. SC is one of the seven states that has a law prohibiting discussions about homosexuality in classrooms, except when discussing sexually transmitted infections (*Comprehensive Health Education Act*, 1988). This perpetuates the myth and stigma that HIV is only linked to homosexual behavior and reinforces that conversations about homosexuality are inappropriate. HIV incidence and prevalence rates are highest among men who have sex with men. Stigmatizing conversations about this lifestyle limit opportunities for healthy dialogue about HIV risk reduction behaviors, testing, and the importance of consistent HIV care.

Other public policy factors, or the local, state and federal laws and policies that regulate behavior, most relevant to HIV care and treatment in the South are Medicaid expansion and the Ryan White Care Act. Healthcare access is vital to HIV viral suppression and health maintenance, and health insurance is typically the key to access. All of the Deep South states, except for Louisiana, opted not to expand Medicaid (Kaiser Family Foundation, 2016). Uninsured HIV patients are left to investigate and navigate vast and varying healthcare systems and may be required to pay expensive medical bills before care is rendered. Fortunately, in 1996 the federal government enacted, and most recently in 2013 reauthorized, the Ryan White Care Act. The mandate requires unfettered access to quality care for people living with HIV and provides over $2 million in funding to over 200 agencies in the Deep South (HRSA, 2019). Yet, a study identified disproportionate funding and HIV medical providers in Southern states in contrast to other U.S. regions (Gilman et al, 2016). This could become a hurdle for a Southern HIV patient that is ready to engage in care, but only has access to a low-capacity Ryan White clinic.

These barriers are compounded by the significant disparities in HIV diagnosis and prevalence in the South. The Deep South has the highest rate and number of people diagnosed with HIV and AIDS of any other US region. Like its HIV rates, the Deep South also has the highest rates of sexually transmitted infections (STIs) compared to any other US region (Reif et al, 2016). STIs have a direct correlation to risk of HIV transmission (Cohen, 2012). High regional rates of disease, as factors in the HIV Epidemic stage of the MSEM, play an important role in determining risk for HIV and implications for care and treatment. In fact, the MSEM is itself useful in understanding the root causes and multiple levels of influence on HIV care and treatment. Strategies to respond to these multi-layered factors are needed, and patient navigation has been identified as a potential option.

2.4 PATIENT NAVIGATION AND CHRONIC DISEASE MANAGEMENT

Much of what we know about patient navigation comes from the world of cancer prevention and control. Wells et al (2018, p. 289) defined basic patient navigation as "identifying and addressing patient needs and barriers; providing information; patient follow up". Using learned tools and strategies, patient navigators are encouraged to build rapport with patients to fully assess and resolve barriers to care, as well as sustain relationships for continued medical adherence.

In 1989, the American Cancer Society published the *Report to the Nation on Cancer in the Poor* and reported that poor Americans with cancer: (1) do not seek care if they cannot afford it; (2) often make "extreme personal sacrifices" to access and afford cancer treatment; (3) may choose not to seek care given perceived fatalist thoughts; (4) are offered "culturally insensitive and irrelevant" education programs; and (5) experience "greater pain and suffering" compared to others (American Cancer Society Report, 1989). In response, the first patient navigation program was developed in 1990 in Harlem, New York by Dr. Harold Freeman (Freeman & Rodriguez, 2011).

Program developers considered the often-short window available to sufficiently link underserved and underprivileged patients to critical care. Patients experienced financial hurdles, lack of insurance coverage, miscommunication from provider to patient, and healthcare distrust – all barriers that reinforced poor health outcomes and are parallel issues within HIV care (Freeman & Rodriguez, 2011). Freeman & Rodriguez (2011) suggest that patient navigation for chronic disease management "be applied across the entire healthcare continuum, including prevention, detection, diagnosis, treatment, and survivorship to the end of life."

According to Freeman (2011), there are nine principles of patient navigation that define and standardize patient navigation programs:

1. *Patient navigation is a patient-centric healthcare service delivery model.*

2. *Patient navigation serves to integrate fragmented healthcare systems for patients.*
3. *The core function of patient navigation is the elimination of barriers to timely care across the care continuum.*
4. *Patient navigation should be clearly defined in practice, distinguishing the role and responsibilities of the patient navigator.*
5. *Patient navigation services should be cost-effective and compliment the skills needed to navigate a patient through a healthcare system and across the care continuum.*
6. *Patient navigators should be selected based on the level of skills needed during each phase of the care continuum.*
7. *When patient navigation will begin, and end should be clearly defined before the onset of the program.*
8. *Patient navigation programs should consider the need to work between different healthcare systems.*
9. *Patient navigation requires consistent coordination and management.*

These principles were informed by over 20 years of practice, and remain relevant today (Freeman & Rodriguez, 2011).

Three models of patient navigation have evolved since its conception that consider the patient navigator's educational background, disease focus, training, health diagnoses, and sociodemographic factors (See Table 2). The first model requires that the patient navigator is from the community served by the patient navigation program, or a "cultural broker and interpreter" (Braun, 2012). The second model requires professional training and includes patient navigators that provide “screening, diagnostic, treatment, and survivorship patient navigation” (Wells, et al, 2018; Hopkins & Mumber, 2009). The third model considers a blend of models one and two. A multidisciplinary team of lay and professional staff collaboratively provide patient navigation, but with a layperson trained by a professional organization (Freeman, 2012 The effectiveness of each PNP models is inconsistent, hence the purpose of this dissertation. More information is needed to better understand which model factors are positively associated with viral suppression, patient engagement, and care retention.

Table 2.2. Patient Navigation Models

Model	Education/Training Required?	Description
1	No	Lay person that identifies with or is a member of the target population who connects patients to services
2	Yes	Trained professional that provides clinical and social support services
3	Yes	Trained lay person and professional working together to provide clinical and social support services

2.5 PATIENT NAVIGATION AND HIV

Patient navigation in HIV is comparable to traditional case management. It is a hybrid of “advocacy, health education, case management, and social work” conducted by trained professionals or paraprofessionals to support positive health outcomes (Bradford et al, 2007). Similarly, case management is defined as “a range of client-centered services that link clients with healthcare, psychosocial, and other services provided by trained professionals (TargetHIV, 2019).” Case management is reserved for trained professionals, and patient navigation can be facilitated by lay or trained professionals.

Nonetheless, both strategies are used to reduce barriers to care and are often used interchangeably.

While research has shown that patient navigation programs for people living with chronic diseases can significantly enhance care processes and outcomes, they have been proven to be inconsistent in their degree of effectiveness at increasing patient retention and viral suppression for people living with HIV (Kelly et al, 2015; Mizuno et al, 2018). The most relevant patient navigation studies are detailed to demonstrate this discrepancy. Eight studies assessed patient retention, and six found positive associations with the navigation program. Six studies assessed viral suppression, and only two found positive associations with the navigation program. Further, these studies highlight vast variability in population, program (intervention), design, and outcome measures and none were exclusive to African Americans from the South.

Gardner et al (2005) described his study as “a case management intervention.” Newly diagnosed patients (n = 273) from four United States metropolitan cities were randomly and evenly assigned to two treatment groups: standard care and case management. Standard care patients were given HIV literature and passively referred to medical care. Case management patients received a maximum of five contacts with a case manager over 90 days and actively linked to medical care. Nearly 80% of case managed patients saw a HIV provider within six months, compared to 60% of standard care patients. Sixty-four percent (64%) of case managed patients saw a HIV provider at least twice within 12 months, compared to 49% of standard care patients. Engagement and retention were shown to be effective, however no clinical outcomes were measured. This is critical deficit given the importance of viral suppression in HIV care.

Wohl et al. (2006) examined 250 adults living with HIV from three HIV clinics in Los Angeles in a six-month study. Patients were assigned to three groups labeled as the directly administered antiretroviral therapy program (DAART), the intensive adherence case management intervention (IACM), and the control group that received standard care. The IACM and control groups incorporated patient navigation, with a higher frequency and intensity provided for the IACM group.

DAART patients were administered medication via a community health worker that noted consumption each weekday for six months. IACM patients self-administered their medication but met with a case manager weekly for six months to discuss barriers to medication adherence and received complimentary social support services (i.e. housing support, insurance assistance, legal aid). The control, or standard of care (SOC) group, self-administered their medication and received the standard quarterly case management services with social support assistance as requested. Eighty-eight percent of the patients were minorities with a high focus on Spanish-speaking Latinos (57%). Researchers found no significant differences in the percentage of virally undetectable patients or CD4+ cell counts between or within any of the intervention groups and attributed results to the inclusion of medication adherence support regardless of medication administration mode. This study assessed clinical outcomes, and though insignificant, results were correlated with medical support – a component of patient navigation.

Though these two earlier studies were inconclusive, four HRSA-funded grantees implemented modified patient navigation programs from 2003 to 2006 and found significant success (Bradford, Coleman, Cunningham, 2007). Participants (n=437) were assessed at baseline, 6-, and 12-months for structural barriers (i.e., problem making an appointment or finding out when to go) and belief barriers (i.e., worries, concerns). Both structural barriers and belief barriers were significantly reduced at 6- and 12-months compared to baseline. Mediators that support positive behaviors (having a case manager, engaging with provider) and health outcomes (undetectable viral load) significantly increased compared to baseline. These results were promising and prompted further exploration into patient navigation as a viable model of care for patients living with HIV.

In a review of patient navigation programs, McBrien et. al (2018) found several studies that suggested positive associations with linkage to care, retention in care, and viral suppression. Five studies examined the effects of a patient navigation program for incarcerated or newly released adults living with HIV (Wohl et al, 2011; Koester et al, 2014; Myers et al, 2018; Cunningham et al, 2018; Fuller et al, 2019). Wohl et al. (2011) randomly assigned inmates living with HIV (n = 104) within the North Carolina Department of Corrections to a case management intervention that emphasized motivational interviewing by a trained HIV case manager. The intervention began three months prior to release and continued for six months thereafter. Control inmates received the standard discharge planning services provided to HIV-infected inmates administered by a prison employee. No significant differences in viremia or CD4+ cell counts between the intervention and control groups were found; moreover, recidivism rates were also similar between the groups. However, the other studies found positive associations with linkage to care (Myers et al, 2018), patient retention (Fuller et al, 2019), viral suppression (Cunningham et al, 2018), and socially concordant patient navigators (Koester et al, 2014).

Three studies of patient navigation incorporated financial incentives to encourage program participation and to reward positive behaviors (Metsch et al, 2015; Metsch et al, 2016; Stitzer et al, 2018). Metsch et al. (2016) evaluated the effectiveness of patient navigation and the use of financial incentives within a population of people living with HIV and a substance abuse disorder. The goal was to improve viral suppression. Eight hundred patients from 11 US hospitals were randomly assigned to receive patient navigation (n = 266; 11 sessions), patient navigation with financial incentives (n = 271; 11 sessions and up to $1,160), and standard care (n = 264). Viral loads were taken at baseline, 6- and 12-months. Financial incentives were provided only if behavioral goals (i.e. mental health counseling, medication adherence) were met. Once more, there was no significant difference in viral suppression between the groups. Metsch et al (2015) and Stitzer et al (2018) also revealed insignificant results between their patient navigation and control groups, suggesting that financial incentives are not essential for program success.

Giordano et al. (2016) was one of the first to introduce and rigorously assess peer mentoring as a component of the patient navigation model for people living with HIV. Over three years (2010 – 2013), hospitalized patients (n = 460) in Houston, Texas who were either newly diagnosed or out of care were randomly and evenly assigned to the patient navigation program or the control group. Intervention patients received two visits by a peer mentor during their hospital stay, and five phone calls within 10 weeks after discharge. Control patients were contacted on the same schedule, but only received information about HIV transmission. The goal was to encourage at least two outpatient visits, and viral load improvement by 6 months post-discharge. Only 28% of patients in both groups accomplished the study’s primary goal. Once more, a statistically significant difference between groups was not observed. Researchers suggested a closer assessment of how the patient's length of stay and when linkage information is delivered affects the peer mentor's effectiveness.

Qualitative studies that included one-on-one interviews with patients and patient navigators support patient navigation as an "evidence-informed strategy" to reduce barriers to care (Cook et al, 2018; Higa et al, 2012; Parnell et al, 2019). Emotional and social support were cited as positive mediators to patient engagement and motivation (Parnell et al, 2019). Figure 7 is provided as a brief summary of the cited patient navigation trials and studies in the Appendix.

Since Gardner et al (2005), the premise of patient navigation in HIV has not changed. These interventions are still developed to improve patient engagement, retention, and health outcomes (Bradford et al, 2007; Wohl et al, 2006; Gardner et al, 2005). However, patient engagement, linkage, and retention have been used interchangeably across studies with varying definitions. A definition of the terms is presented below for clarity and consistency:

- *Linkage: To connect or refer a patient to a medical provider for routine HIV care*
- *Engagement: The ongoing interaction of patients, their providers, and care settings that is characterized by a patient's sense of connection to and active participation in care (Johnson et al, 2017)*
- *Retention: At least one medical visit in each 6-month period of a 24-month measurement period with a minimum of 60 days between medical visits (HRSA, 2019)*

More research is needed to determine if patient navigation programs objectively provide clinical value for patients living with HIV, or if they should be solely used to provide emotional and social support. The research highlighted in text and summarized in Appendix A presents key patient navigation program attributes that should be modified and re-evaluated to determine effectiveness.

2.6 PEER NAVIGATION AT PALMETTO STATE HIV CENTER

Since the inception of Palmetto State HIV Center in 2000, the team and available services have grown in scale and scope, becoming an integral part of the region's healthcare network and the local community. As the center's patient population continues to increase, it remains overwhelmingly African American. More than 67% of enrolled patients are African American, although they account for only 34% of the region's total population census. Over 96% of patients have received at least two medical visits in the past year, with visits being at least six months apart. Yet, the center's African American patients continue to represent a large proportion of patients that are considered to be "lost to care." Of patients lost to care in 2017, 86% were African American. This represents a considerable public health challenge, as out-of-care patients tend to have unsuppressed HIV viremia and to be co-infected with other STIs (Meissner, 2018).

When the Peer Navigation Program (PNP) began in 2014, it was one of the first for a Ryan White program in the state. Funding for the pilot initiative was provided by a HRSA HIV/AIDS Bureau (HAB) Ryan White Part C Capacity Development Grant. The grant specifically requested interventions that addressed health disparities for priority populations: African Americans, men who have sex with men (MSM), transgender women, and youth (ages 18 – 24). Palmetto State perceived the PNP as an opportunity to address the viral suppression and patient retention disparities among its African American population. The PNP provides non-clinical support during the patient engagement, re-engagement and retention process to address healthcare barriers and disparities. In the PNP model, patients in the program are counseled by a trained navigator who is also living with HIV (i.e., "peer navigators"). The shared experience of learning about and living with HIV is significant in that it cannot be feigned and can be traumatizing (Ryan White Wellness Center, 2015).

Since the inception of the PNP in 2014, 500 patients have been introduced and 125 (25.0%) have accepted the supplemental service and are actively engaged with the Peer Navigators (Ryan White Wellness Center, 2019). All newly enrolled patients of Palmetto State are referred to a Peer Navigator within 24-48 hours post enrollment. Peer Navigators then have 48 hours to contact the patient by telephone or during an in-person meeting. During the initial consult, the Peer Navigators explain that the purpose of the program is to help the patient increase retention and reach viral suppression by offering social support. Navigators also give their own experience living with HIV to build trust and rapport, and model diagnosis disclosure. Patients that choose to enroll in PNP are logged; mode and frequency of continued communication is determined by the needs of the patient. Each interaction is documented and reviewed, as needed, with the patient's care team (Ryan White Wellness Center, 2019).

2.6.1 PEER NAVIGATION AT PALMETTO STATE HIV CENTER: PRELIMINARY EVALUATION

Funding for the PNP was granted in 2014. Preliminary data at the time that the grant ended in 2015 were favorable, but marginal. Only 30 patients voluntarily enrolled in the PNP at that time. Of the 30 PNP patients, viral suppression rates increased by 46% and patient retention increased by 52%. Yet, the most significant program benefits of peer navigation were often intangible and difficult to quantify. The experience of engaging with a paraprofessional with a shared diagnosis had a profound impact on the way patients connected with their care. Anecdotally, patients that engaged in the PNP expressed an improved sense of engagement and purpose in their care (Ryan White Wellness Center, 2015).

Having been in existence for five years, there is a need to clearly define and evaluate the long-term impact of the PNP and determine the program's strengths, limitations and opportunities. A logic model was developed retroactively for this study as an essential component to initiate the evaluation process (See Figure 6). A logic model is a graphic depiction of program procedures necessary to reach a desired outcome. It shows the causal linkages between the activities of the program staff and participants that result in initial, intermediate, and long-term outcomes. Although the goal of the program is to increase viral suppression and retention, there are several transitional goals that would also signal program success, namely increased patient knowledge of HIV, local resources, and skills to navigate the healthcare system. Organizationally, the center could learn more about patient barriers to medical adherence, and strategies and services to address these barriers. The logic model will help to guide evaluation activities for the proposed research but can continue to be used by the center's staff for ongoing monitoring and evaluation.

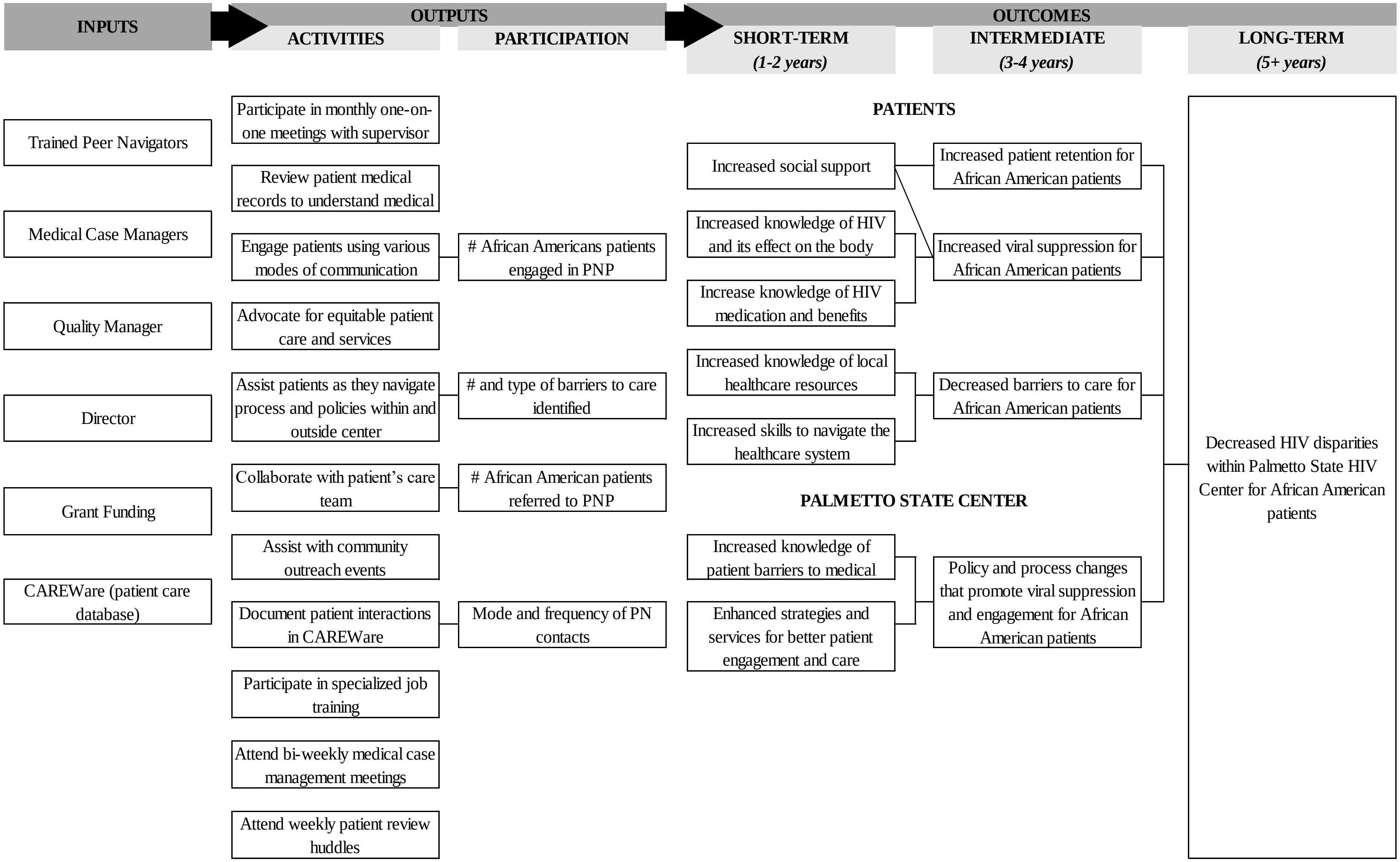

Figure 2.4. Palmetto State HIV Center PNP Logic Model

CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 SIGNIFICANCE

Research suggests that patient navigation is a strategy that could be employed to reduce barriers to care for adults living with a chronic disease (Freeman, 2012). First developed to engage underserved cancer patients, the concept has been explored by researchers and practitioners to enhance care for adults living with HIV (Mizuno et al, 2018). However, the review of literature supports that more research is needed to determine whether patient navigation programs are beneficial for people living with HIV; and if so, which components may have the greatest utility. The evidence is inconsistent. This study also contributes to the limited body of literature available about African American patients in clinical settings. Moreover, findings have direct application by guiding program modifications to decrease HIV-related disparities for the Palmetto State HIV Center’s African American patients. The information collected during this project:

(1) Determined the effectiveness of a Peer Navigation Program (PNP) for African American adults living with HIV using objective and biological HIV care metrics (such as number of appointments and viral load collected from medical records) to assess patient engagement, care retention, viral load changes, and achievement of viral suppression;

(2) Qualitatively assessed delivery characteristics of the Peer Navigation Program (PNP) and cognitive-behavioral factors associated with participation for African American adults living with HIV using individual interviews of PNP patients.

This study contributes to the refinement of current research, but also challenges practitioners to explore innovative approaches to care that can be integrated within the traditional healthcare model.

3.2 STUDY DESIGN

This study used a convergent triangulation mixed method design to evaluate the impact of the Peer Navigation Program at the Palmetto State HIV Center on care retention (CR), medication adherence (MA) and viral suppression (VS) among African American adult patients living with HIV and enrolled at the Center. Convergent mixed method designs allow for data to be collected in parallel timeframes and then merged for full analysis (Fetters, Curry, Creswell, 2013; See Figure 7). Data collection and analysis are done concurrently. Then, all information is compared to determine trends, themes, and significance. The qualitative data gives illustrative context to the quantitative results, and this model is advised for such use. According to Creswell and Clark (2011), this model should be used to develop well-founded conclusions about a single event or intervention.

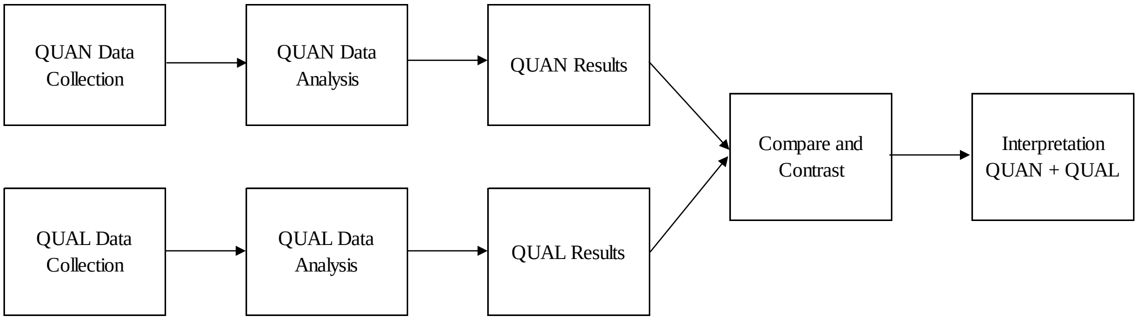

Figure 3.1. Convergent Triangulation Mixed Methods Design

The quantitative arm of the study used a matched case-control study design to conduct a cross-sectional and case-cohort analysis using data extracted from medical records. The qualitative arm of this study explored the contextual (organizational) factors that influence program participation to further inform quantitative outcomes.

Patient health records of African American adults in the PNP from January 1, 2016 to December 31, 2018 was used to (1) assess patient engagement, retention, and viral suppression using a pre/post evaluation and (2) compare African American adult PNP patients against African American adult patients during the outlined timeframe who never participated in the PNP. In addition, patients were interviewed to explore contextual and organizational factors that influence program participation.

3.2.1 SETTING AND SAMPLE

Palmetto State HIV Center is a federally funded outpatient clinic in Charleston, SC for people living with HIV or at high risk for HIV acquisition. The Center offers a multidisciplinary approach to patient care providing onsite access to a medical team, social workers, mental health counseling, a pharmacy, food pantry, housing assistance and a list of other supplemental services. Patients are routinely scheduled for medical appointments every three to six months (contingent on medical stability), and case management appointments every six months. Medical and case management appointments are often co-scheduled to increase efficiency for the patient and encourage medical compliance. Today, the center serves over 950 patients (HIV, n = 826; Non-HIV, n = 142) from seven counties along the southeastern border of SC. Patient demographics of active patients living with HIV as of November 2020 are represented in Table 3 (Ryan White Wellness Center, 2019).

Table 5 lists participant demographic information. The participants for this study are African American patients who were enrolled in the PNP between January 1, 2016 and December 31, 2018. Of the Palmetto State HIV Center's 800 patients living with HIV during the study period, 64.6% (n=517) were African American; and 15.5% (n=124) were enrolled in the Peer Navigation Program. The study sample consists of male (n=82), female (n=39), and transgender (n=3) patients ranging in age from 18 years-old to 89 years-old. Of the 124 PNP patients, 79.8% (n=99) were insured by a federal or private insurance plan.

Table 3.1. Palmetto State HIV Center Patients Demographic Characteristics

		Palmetto State HIV Center HIV Patients (N = 826)	
		N	%
Gender	Male	597	72.3
	Female	222	26.9
	Transgender	7	0.8
Age	18 – 24 years	42	5.1
	25 – 29 years	89	10.8
	30 – 39 years	140	16.9
	40 – 49 years	172	20.8
	50 – 59 years	234	28.3
	60+ years	144	17.4

		Palmetto State HIV Center HIV Patients (N = 826)	
		N	*%*
Race	Black	532	64.4
	White	272	32.9
	Other	22	2.7
Insurance Status	Medicaid/Medicare	231	28.0
	Private – Employer	167	20.2
	Private – Individual	218	26.4
	Uninsured	62	7.5
	VA/Tricare	6	0.7
	Other/Unidentified	137	16.6
Ever enrolled in PNP	No	626	75.8
	Yes	200	24.2

Table 3.2. Patient Participants Demographic Characteristics, Jan 2016 – Dec 2018

		African American Patients, Total (N=517)		African American Patients, PNP (N=124)	
		n	*%*	*n*	*%*
Gender	Male	347	67.1	82	66.1
	Female	166	32.1	39	31.5
	Transgender	4	0.8	3	2.4
Age	18 – 24 years	13	2.5	7	5.6
	25 – 29 years	59	11.4	19	15.3
	30 – 39 years	109	21.1	38	30.6
	40 – 49 years	98	19.0	19	15.3
	50 – 59 years	147	28.4	27	21.8
	60+ years	91	17.6	14	11.3
Insurance Status	Medicaid/Medicare	181	35.0	39	31.5
	Private – Employer	111	21.5	17	13.7
	Private – Individual	154	29.8	40	32.3
	Uninsured	60	11.6	25	20.2
	VA/Tricare	5	1.0	2	1.6

Other/Unidentified	1	0.2	1	0.8

3.2.2 AIM 1: QUANTITATIVE STUDY

3.2.2.1 Patient Sampling and Recruitment Considerations. Medical records for all African American patients receiving care at the Palmetto State HIV Center during the testing period (January 2016 to December 2018) were extracted from two electronic medical record platforms – eClinicalWorks and CAREWare, a HRSA-built and managed platform. Although the PNP program started in 2014, this was the pilot year and included many process changes as program strengths and weaknesses were noted. The next year, 2015, served as a more stable and refined program year with complimentary policies and procedures. Hence, this study evaluated metrics for the following year (2016) with the assumption of less programming variability.

A matched case-control design allows the researcher to extract a sample of treatment patients, then match a random control patient based on perceived confounding variables. This improves the study's efficiency and validity (Rose & Van Der Laan, 2009). A stepwise matched process resulted in 96 African American patients being included in this exploratory matched case-control study. Table 5 outlines the quantitative patient participant demographics. Forty-eight (48) PNP patients were randomly matched with 48 Non-PNP patients controlling for gender, age group, initial CD4 count, and self-reported HIV risk factor (heterosexual, MSM, not specified).

Patients who were discharged, terminated, incarcerated or died during the testing period were removed from the study sample. In addition, patients with incomplete medical records were also excluded. The remaining study sample of PNP reduced from 124 patients to 59 patients. Of the 59 PNP eligible patients enrolled for the entire study period, 81.3% (n=48) of PNP patients were matched. The remaining 19.0% (n=11) of the eligible PNP patients were excluded because no match control was found due to one or two mismatches with the outlined match variables. Eight did not match due to age, two due to CD4 count and one due to HIV risk factor.

Table 3.3. Quantitative Patient Participant Demographic Characteristics

		African American Patients, Non-PNP (N=48)		African American Patients, PNP (N=48)	
		n	*%*	*n*	*%*
% Participants			50.0		50.0
Gender	Male	30	62.5	30	62.5
	Female	18	37.5	18	37.5
	Transgender	0	0.0	0	0.0
Age	18 – 24 years	1	2.1	1	2.1
	25 – 34 years	12	25.0	12	25.0
	35 – 49 years	13	27.1	13	27.1
	50+ years	22	45.8	22	45.8
Self-Reported HIV Transmission Mode	Heterosexual Contact	27	56.3	27	56.3
	MSM	17	35.4	17	35.4
	Other	4	8.3	4	8.3

3.2.2.2 Measures. De-identified patient clinical data, including age, gender, PNP participation, viral load, CD4 count, HIV transmission mode, and number of medical appointments were downloaded from CAREWare to an Excel file on a password encrypted computer. CD4 counts were converted using high, medium, and low scales. A CD4 count greater than 500 cells/mm3 was coded as high, 201 – 500 cells/mm3 was coded as medium, and less than 200 cells/mm3 was coded as low.

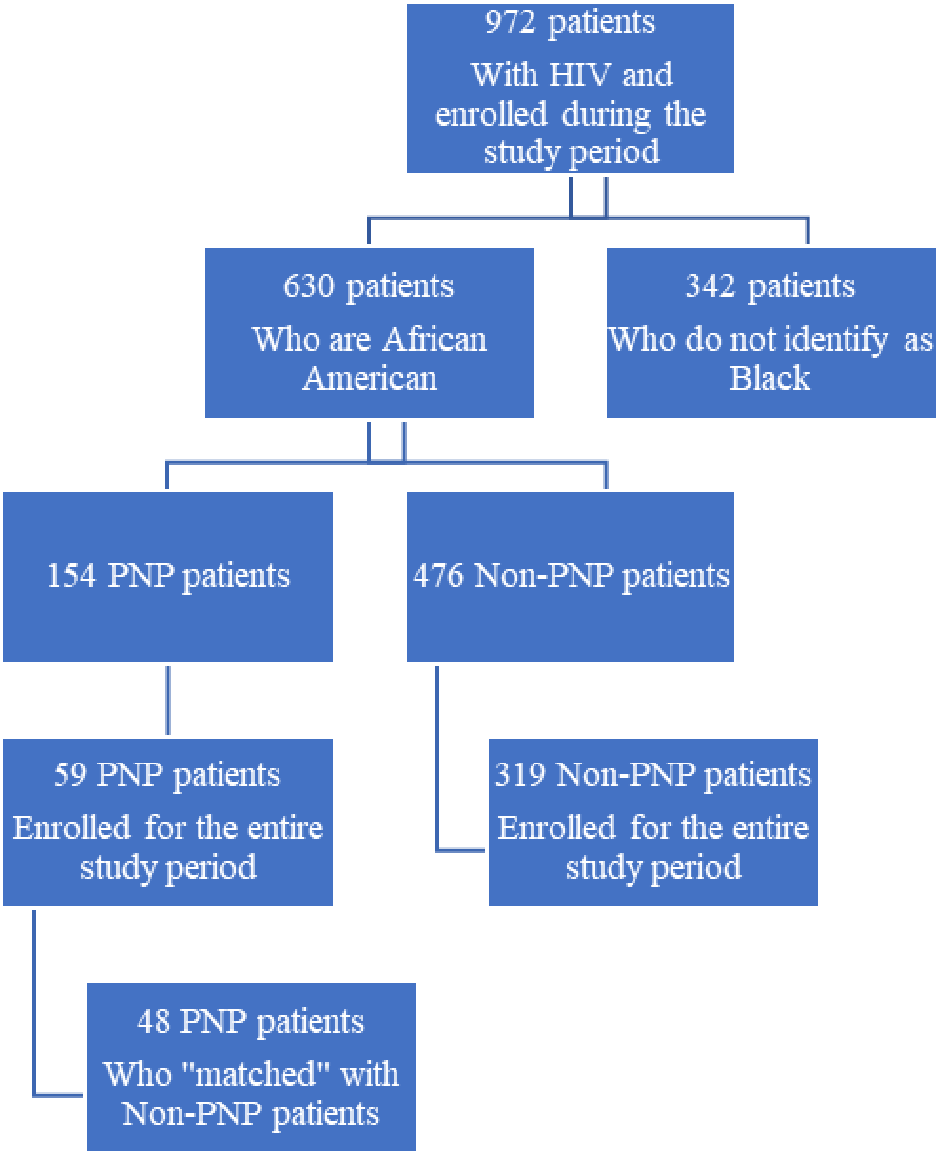

Figure 3.2. Quantitative Patient Matching Process

Next, viral load and number of medical appointments were converted to categorical variables (yes/no) to indicate viral suppression, engagement and retention. Viral suppression is defined as having less than 200 copies of HIV per milliliter of blood (CDC, 2020). If a patient's viral load was less than 200 copies/mL, it was coded as "yes" to indicate viral suppression. Number of appointments was used to measure engagement for each calendar year and retention for a 24-month span (2016 – 2018). For this study, an objective measure—HRSA's care engagement definition is used (2019): at least one medical visit in each 6-month period of a 12-month measurement period with a minimum of 90 days between medical visits. Retention is defined as at least one medical visit in each 6-month period of a 24-month measurement period with a minimum of 90 days between medical visits (HRSA, 2019). Comparable to viral suppression, patients with at least two appointments with a minimum of 90 days between medical visits for each calendar year were coded as "yes" to indicate engagement. Patients with at least four appointments with a minimum of 90 days between medical visits for the 24-month span were coded as "yes" to indicate retention.

3.2.2.3 Data Analysis and Management. Viral suppression, care engagement and care retention were analyzed using SPSS Version 26 analytical software. Patients enrolled in the PNP were compared to themselves prior to PNP enrollment and to African American patients that were never enrolled in the PNP. Frequency tables will be generated to describe the population. Categorical outcome variables, viral suppression, retention and engagement, were assessed used non-parametric tests. To assess differences within the PNP group, the McNemar test was used and validated using a binomial sign test. To assess differences between the PNP and Non-PNP groups, chi-square test was used given there are only two groups. P-values less than 0.10 were statistically significant.

3.2.3 AIM 2: QUALITATIVE STUDY

3.2.3.1 Patient Sampling and Recruitment Considerations. Patients were invited to participate in an interview via contact by his/her/their respective case manager. However, this proved to be ineffective. Patients did not respond to email invitations and referrals by case managers were minimal (less than 5) after three weeks of recruitment. Moreover, the hospital system was forced to close offices and significantly reduce patient visits due to COVID-19. All case managers were required to work from home and patient interaction was reduced to phone and video calls. As a result, the center's receptionist was enlisted to assist with patient recruitment. She was still working in the office every day despite the COVID-19 restrictions and had more opportunities to engage patients.

A script and recruitment flyer were provided to explain the study to solicit patient participation. The script was comparable to the email that was sent to prospective participants. The script and email detailed the purpose of the study, risks and benefits of participation, incentive for participation, and that participation is voluntary and will be kept confidential.

Fifteen patients agreed to participate in interviews. A little over half of interview participants were male (53.3%), and ages ranged from 22 to 70. All were African American, 60.0 were not married, and none were uninsured. Moreover, 46.7% were diagnosed with AIDS and 40.0% were enrolled in the PNP. Additionally, selection bias is quite common within voluntary programming. As one would expect, those that volunteer for the activity are probably more proactive about their sexual health, thereby reporting outcomes and/or experiences that are unlike the general population. Participant demographics are represented in Table 6.

Table 3.4. Qualitative Patient Participant Demographic Characteristics

		African American Interview Patients (N=15)	
		n	%
Participants			
Gender	Male	8	53.3
	Female	7	46.7
	Transgender	0	0.0
Age	18 – 24 years	1	6.7
	25 – 29 years	0	0.0
	30 – 39 years	2	13.3
	40 – 49 years	3	20.0
	50 – 59 years	6	40.0
	60+ years	3	20.0
Marital Status	Single	9	60.0
	Married	2	13.3
	Separated/Divorced/Widowed	4	26.7
Insurance Status	Medicaid/Medicare	8	53.3
	Private - Employer	2	13.3
	Private - Individual	5	33.3
	VA/Tricare	0	0.0
	Uninsured	0	0.0
AIDS Diagnosis	Yes	7	46.7
	No	8	53.3
Enrolled in the PNP	Yes	6	40.0
Enrolled in the PNP	No	9	60.0

3.2.3.2 Data Collection. Because of my professional role at Palmetto State, interviews were conducted by an independent consultant to encourage honesty and transparency. Semi-structured individual interview guides were loosely framed to encourage relaxed, conversational communication. This method warrants flexibility and allows probing for details (Powell & Steele, 2009). The interview guide was conceptualized using the MSEM levels. Patients were asked to discuss their experience living with HIV, supports and barriers to remaining in care, and experience (if any) with the Center's PNP. If the patient was not enrolled in the PNP, they were asked for suggested characteristics of an effective PNP. All interviews were conducted by phone due to COVID-19 quarantine requirements. Zoom and WebEx was preferred but proved to have varying connectivity, so the phone became the most reliable mode of communication.

Interviews were recorded using a digital voice recorder and transcribed using Temi, an online transcription service. A short patient questionnaire was used to collect social demographics like age, gender, marital status, and consent was granted verbally. The interviews took no more than 30 minutes and patient interviewees were given a $25 VISA gift card for their participation. The interview guide and questionnaire can be found in Appendix D.

Effectively measuring the validity and reliability of study results is vital given my professional role at the center. Johnson (1997) refers to three types of validity that can be addressed within qualitative research: descriptive, interpretive, and theoretical. Based on the intended data to be collected and purpose of the study, descriptive and interpretive validity were most considered and confirmed. Descriptive validity is the extent to which factual information is accurately reported by the researcher, and interpretive refers to the degree that those views, opinions, and thoughts obtained and reported are accurately understood (Johnson, 1997). Each was assessed through triangulation and member-checking with the independent consultant and the dissertation committee chair.

3.2.3.3 Data Analysis and Management. All interviews were electronically transcribed from the audio recording. Transcripts were reviewed for accuracy by simultaneously reading the transcript and listening to the recording. A directed content analysis of transcribed data was conducted using pre-established themes based on the interview guide and emergent themes that arise organically from the interviews. Significant quotes are included as examples of the themes. Routine data reviews with my dissertation chair allowed opportunities to vet and validate themes and quotes until a consensus was met.

Despite a small sample size, saturation was attained. Guest et. al. (2006) define saturation as the basis on which no new information is discovered and data collection should be discontinued. He also suggests that this occurs at or about 12 interviewees within a homogenous group. Under this guidance, it was plausible that saturation was achieved with the 15 African American patients interviewed. They were not all members of the PNP, but were homogeneously connected to the Palmetto State HIV Center sharing comparable experiences.

A directed content analysis of transcribed data was conducted using pre-established themes based on the interview guide and emergent themes that arose organically from the interviews. Compared to a conventional or summative content analysis, a directed content analysis is used when “existing theory or prior research exists about a phenomenon that is incomplete or would benefit from further description" (Hsieh and Shannon, 2005; p. 1281). This also allows codes and themes to be developed before and during data collection and analysis. Key information was highlighted and categorized using the identified codes and themes. Manual coding was preferred given the small sample size. However, the data was electronically maintained on a password-encrypted computer.

3.3 BUDGET

A budget of $875 was required to facilitate this study and was funded by the student. A $25 VISA gift card was provided to each interview participant (15) and the independent consultant was paid $500 to facilitate said interviews.

3.4 ETHICS AND PROTECTION OF HUMAN SUBJECTS

This study posed minimal to no risk to participants. Patient data was de-identified and only aggregate data was reported. All data was managed on one secure, password-encrypted computer. Interview participants that felt uncomfortable discussing their HIV diagnosis and care were given permission to pass questions without penalty and encouraged to only share at their comfort level. Moreover, patient participants were reassured that there would be no retaliation for negative opinions and findings will only be used to help improve the PNP, where necessary.

This study received approval from the institutional review boards of the University of South Carolina – Columbia and the study site's Institutional Review Board. The name of the site is not included to protect the identity of the healthcare center and its patients. Certification for the completion of CITI's Human Research for Social and Behavioral Researchers was also ascertained in January 2020.

3.5 DISSEMINATION

Study results will be shared with the staff of the Palmetto State HIV Center, and patient participants. Results may also be shared by Palmetto State staff during professional meetings and conferences.

CHAPTER 4

RESULTS

4.1 INTRODUCTION

The convergent mixed methods design allowed quantitative and qualitative data to be collected simultaneously. Though this method has its advantages, for this study it yielded results that were inconsistent with the stated specific aim outlined in Chapter 1. The interview guides used for PNP and Non-PNP patients, while developed to better understand factors that encourage or discourage participation, produced more information about the overall perception of care and desired care characteristics at Palmetto State HIV Center compared to that shared specifically about the PNP program

Study limitations related to COVID-19 limited the number of patients in the PNP that could be recruited to be interviewed. In addition, findings revealed that some patients in the PNP were not even aware they were enrolled. This impacted responses in a way that could not have been anticipated based on initial specific aim. After thorough analysis, the findings are different from what was expected, thus changing the overall approach to Specific Aim 2. Nonetheless, the data collected are rich in content and context, and provide useful insight into patient’s perceived and desired care characteristics. These findings are presented in the second manuscript.

CHAPTER 5

EXPLORATORY MATCHED CASE-CONTROL STUDY OF A CLINIC-BASED PATIENT NAVIGATION PROGRAM ON PATIENT RETENTION AND VIRAL SUPPRESSION AMONG AFRICAN AMERICANS LIVING WITH HIV IN THE SOUTH[1]

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[1] Willis, K.B., Robillard, A., Ingram, L., Spencer, M., and Smallwood, S. To be submitted to *AIDS Care*.

5.1 ABSTRACT

5.1.1 INTRODUCTION

The transition of HIV from a fatal disease to a chronic condition requires important disease management considerations and innovative approaches for patient care. Despite medical and technological advancements, African Americans contract, live with, and die due to HIV-related complications at disproportionately higher rates compared to their White peers. The purpose of this exploratory case-control study is to evaluate the effectiveness of a clinic-based Peer Navigation Program (PNP) on viral suppression, engagement and retention among African Americans living with HIV in South Carolina and receiving care from a Ryan White clinic.

5.1.2 METHODS

A stepwise process resulted in 96 African American patients being included in this exploratory matched case-control study. Forty-eight (48) PNP patients were randomly matched with 48 Non-PNP patients controlling for gender, age, initial CD4 count, and self-reported HIV risk factor. The study sample consisted of male (n=60) and female (n=36) patients that were 18 years-old or older. Patient data were analyzed to determine within and between group differences in viral suppression, engagement, and retention. To assess differences within the PNP group, the McNemar test was used and validated using the binomial sign test. To assess differences between the PNP and Non-PNP groups, chi-square tests were used given there are only two groups. P-values less than 0.10 were statistically significant.

5.1.3 RESULTS

Viral suppression improved from initial measurements to follow up for PNP patients, and a higher than expected proportion of PNP patients were engaged each year of the study. However, there were no significant changes in viral suppression, patient engagement or retention between the PNP and Non-PNP patient groups.

5.1.4 CONCLUSION

The effect of patient navigation within HIV care have been inconsistent, yet this study suggests some positive impact. The PNP was designed to help critically ill or unstable patients improve their health outcomes, and it improved viral suppression for the highly engaged at-risk patient group. A process evaluation may yield more information to identify and enhance factors that can further support these outcomes.

5.1.5 KEY WORDS

HIV, Patient Navigation, South Carolina, Viral Suppression, Patient Engagement, Care Retention

5.2 INTRODUCTION

The transition of HIV from a fatal disease to a chronic condition requires important disease management considerations and innovative approaches for patient care. Antiretroviral medication has been approved to treat HIV since March 19, 1987 (USFDA, 2018). Although treatment was available, unfettered access was not available until 1996 with the inception of the US AIDS Drug Assistance Program (ADAP), resulting in a great decline of AIDS deaths over the decades (Meissner, 2018). Despite this, there was still a significant and consistent racial disparity among AIDS deaths. African Americans contract, live with, and die because of HIV-related complications at disproportionately higher rates compared to their White peers.

In 2000, the CDC standardized the definition of AIDS to allow equitable comparisons across years (CDC, 2001). A patient was diagnosed with AIDS when his/her CD4 cell count dropped below 200 cells/mm, or if they developed specific opportunistic infections (CDC, 2001). In that year, 37.8% (n = 292,522) of diagnosed with AIDS in the United States were African American; of the 58% (n = 448,060) who died due to AIDS-related complications, 61% were African American or Hispanic (CDC, 2001). In 2016, only 2% (n = 525,374) of people living with AIDS died; yet 61% were African American or Hispanic (CDC, 2019).

Geographically, African Americans in the Southern region carry the greatest burden of HIV. The lower, southeastern region of the United States (AL, FL, GA, LA, MS, NC, SC, TN, TX) has the highest rate and prevalence of people diagnosed with HIV and AIDS of any other US region, and African Americans are disproportionately impacted (Reif, et al, 2019). According to the Southern HIV/AIDS Strategy Initiative, African Americans living with HIV in the Deep South account for 53% of HIV diagnoses in the region (Reif, et al, 2019). However, the racial group only comprised 24.7% of the region’s population (US Census, 2011). South Carolina has the sixth highest incidence rate and fourth highest prevalence rate of the aforementioned Southern states (CDC, 2018). Rates of HIV for African American men and women in SC are nearly 6 and 18 times higher compared to White men and women, respectively (CDC, 2018).

Medication adherence is essential to achieve viral suppression, increase life expectancy, and prevent HIV (Meissner, 2018). Medical research has led to a simplified

HIV treatment regimen that combines drugs into small, single-dose tablets called highly active antiretroviral therapy (HAART). This evolution of HIV medication has created cleaner, safer drugs, yet access to the drugs and prescribing providers still serve as a barrier for African American patients, thus maintaining health disparities. HIV patients have cited lack of insurance, cost of care, organization and delivery of healthcare, and transportation as significant barriers to accessing care and treatment (Dombrowski et al, 2015; Yehia et al, 2015). HIV also carries a burden of shame and stigma that are counterproductive to effective and sustained treatment (Hutchinson & Dhairyawan, 2018).

Patient navigation is a strategy identified to help improve essential HIV care metrics by promoting care and medication adherence. For HIV, patient navigation is comparable to traditional case management. It is a hybrid of "advocacy, health education, case management, and social work" conducted by trained professionals or paraprofessionals to support positive health outcomes (Bradford et al, 2007). Similarly, case management is defined as "a range of client-centered services that link clients with healthcare, psychosocial, and other services provided by trained professionals (TargetHIV, 2019)." Case management is reserved for trained professionals, and patient navigation can be facilitated by lay or trained professionals. Both strategies are used to reduce barriers to care and are often used interchangeably.

Patient navigation programs for people living with chronic diseases can significantly enhance care processes and outcomes; however, results have been inconsistent in terms of whether these programs are effective at increasing patient retention and viral suppression for people living with HIV (Kelly et al, 2015; Mizuno et al, 2018). In a study described as “a case management intervention,” newly diagnosed patients (n = 273) from four United States metropolitan cities were randomly and evenly assigned to two treatment groups: standard care and case management Gardner et al (2005). Standard care patients were given HIV literature and passively referred to medical care. Case management patients received a maximum of five contacts with a case manager over 90 days and actively linked to medical care. Nearly 80% of patients who were case managed saw a HIV provider within six months, compared to 60% of standard care patients. Sixty-four percent (64%) of case managed patients saw a HIV provider at least twice within 12 months, compared to 49% of standard care patients. Engagement and retention in care were shown to be effective, however no clinical outcomes were measured..

Four HRSA-funded grantees implemented modified patient navigation programs from 2003 to 2006 and found significant success (Bradford, Coleman, Cunningham, 2007). Participants (n=437) were assessed at baseline, 6-, and 12-months for structural barriers (i.e., problem making an appointment or finding out when to go) and belief barriers (i.e., worries, concerns). Both structural barriers and belief barriers were significantly reduced at 6- and 12-months compared to baseline. Mediators that supported positive behaviors (having a case manager, engaging with provider) and health outcomes (undetectable viral load) significantly increased compared to baseline. These results were promising and prompted further exploration into patient navigation as a viable model of care for patients living with HIV.

In a review of patient navigation programs, McBrien et. al (2018) found several studies that suggested positive associations with linkage to care, retention in care, and viral suppression. However, five studies conducted from 2006 to that found no significant results or associations for viral suppression, engagement and/or retention (Wohl et al, 2006; Wohl et al, 2011; Giordano et al, 2016; Metsch et al, 2016; Stitzer et al, 2018). The premise of patient navigation is still to improve patient engagement, retention, and health outcomes (Bradford et al, 2007; Wohl et al, 2006; Gardner et al, 2005). More research is needed to determine if patient navigation programs objectively provide clinical value for patients living with HIV, or if they should be solely used to provide emotional and social support. This study evaluated the impact of a Peer Navigation Program (PNP) at the Palmetto State HIV Center on engagement, retention and viral suppression among its African American adult patients.

5.3 METHODS

5.3.1 STUDY POPULATION

Palmetto State HIV Center is a federally funded outpatient clinic in a metropolitan area of SC for people living with HIV or at high risk for acquiring HIV. The Center offers a multidisciplinary approach to patient care providing onsite access to a medical team, social workers, mental health counseling, a pharmacy, food pantry, housing assistance and a list of other supplemental services. Patients are routinely scheduled for medical appointments every three to six months (contingent on medical stability), and case management appointments at minimum every six months. Medical and case management appointments are often co-scheduled to increase efficiency for the patient and encourage medical compliance. The Center currently serves over 950 patients (HIV, n = 826; Non-HIV, n = 142) from seven counties in the state. However, there were only 800 patients living with HIV during this study’s test period (Jan 1, 2016 – Dec 31, 2018).

When the PNP began in 2014, it was one of the first funded by the HRSA HIV/AIDS Bureau in the state. This funding specifically requested interventions that addressed health disparities for priority populations: African Americans, men who have sex with men (MSM), transgender women, and youth (ages 18 – 24). Palmetto State perceived the PNP as an opportunity to address the viral suppression and patient retention disparities among its African American population. The PNP provides non-clinical support during the patient engagement, re-engagement and retention process to address healthcare barriers and disparities. In the Center's PNP model, patients in the program are counseled by a trained navigator who is also living with HIV (i.e., "peer navigators"). The shared experience of learning about and living with HIV is significant in that it cannot be feigned and can be traumatizing (Ryan White Wellness Center, 2015).

Since the inception of the PNP in 2014, 200 patients have accepted the supplemental service and actively engaged with the Peer Navigators (Ryan White Wellness Center, 2019). All newly enrolled patients of Palmetto State are referred to a Peer Navigator within 24-48 hours post enrollment. Peer Navigators then have 48 hours to contact the patient by telephone or during an in-person meeting. During the initial consult, the Peer Navigators explain that the purpose of the program is to help the patient increase retention and reach viral suppression by offering social support. Navigators also give their own experience living with HIV to build trust and rapport, and model diagnosis disclosure. Mode and frequency of continued communication is determined by the needs of the patient. Each interaction is documented and reviewed, as needed, with the patient's care team (Ryan White Wellness Center, 2019).

Table 3.3 lists participant demographic information. The participants for this study were African American patients who were enrolled in the PNP between January 1, 2016 and December 31, 2018. Although the Peer Navigation Program started in 2014, this was the pilot year and included many process changes as program strengths and weaknesses were noted. The following year, 2015, served as a more stable and refined program year with complimentary policies and procedures. Hence, this study evaluated metrics for the following year (2016) with the assumption of less programming variability.

Of the Palmetto State HIV Center's 800 patients living with HIV during the study period, 64.6% (n=517) were African American; and 15.5% (n=124) were enrolled in the PNP. A stepwise process resulted in 96 African American patients being included in this exploratory matched case-control study. Forty-eight (48) PNP patients were randomly matched with 48 Non-PNP patients controlling for gender, age group, initial CD4 count, and self-reported HIV risk factor as described in pre-determined HRSA database categories (heterosexual, MSM, Not Specified). HIV risk factor could also be interpreted as primary transmission mode. One patient identified as an intravenous drug user (IDU); but, was mismatched with the control population and not included in this analysis.

Patients who were discharged, terminated, incarcerated or died during the testing period were removed from the study sample. In addition, patients with incomplete medical records were also excluded. The remaining study sample of PNP reduced from 124 patients to 59 patients. Of the 59 PNP eligible patients enrolled for the entire study period, 81.3% (n=48) of PNP patients were matched. The remaining 19.0% (n=11) of the eligible PNP patients were excluded because no match control was found due to one or two mismatches with the outlined match variables. Eight did not match due to age, two due to CD4 count and one due to HIV risk factor. See Figure 1 for a graphic of the stepwise process.

5.3.2 STUDY PROTOCOL

Medical records for all African American patients during the testing period (January 2016 to December 2018) were examined to determine within and between group differences in engagement, retention, and viral suppression using SPSS Version 26 analytical software. Medical records were accessed from CAREWare, a HRSA-built and managed electronic medical record platform used by the Center. African American patients enrolled in the PNP were compared at baseline (the beginning of the study period, January 2016) and follow-up (December 2018), and to African American matched control patients that were never enrolled in the PNP. The study protocol was approved by the University of South Carolina – Columbia Institutional Review Board and the study site's Institutional Review Board.

5.3.3 MEASURES

De-identified patient clinical data, including age, gender, PNP participation, viral load, CD4 count, HIV transmission mode, and number of medical appointments were downloaded from CAREWare to an Excel file on a password encrypted computer. CD4 counts were converted using high, medium, and low scales. A CD4 count greater than 500 cells/mm3 was coded as high, 201 – 500 cells/mm3 was coded as medium, and less than 200 cells/mm3 was coded as low.

Next, viral load and number of medical appointments were converted to categorical variables (yes/no) to indicate viral suppression, engagement and retention.

Viral suppression is defined as having less than 200 copies of HIV per milliliter of blood (CDC, 2020). If a patient's viral load was less than 200 copies/mL, it was coded as "yes" to indicate viral suppression. Number of appointments was used to measure engagement for each calendar year and retention for a 36-month span. For this study, an objective measure—HRSA's care engagement definition is used: at least one medical visit in each 6-month period of a 12-month measurement period with a minimum of 90 days between medical visits. Retention is defined as at least one medical visit in each 6-month period of a 24-month measurement period with a minimum of 90 days between medical visits (HRSA, 2019). An additional year was considered for patient retention to increase the stringency of the measure given required visits by the center. Comparable to viral suppression, patients with at least two appointments with a minimum of 90 days between medical visits for each calendar year were coded as "yes" to indicate engagement. Patients with at least six appointments with a minimum of 90 days between medical visits for the 36-month span were coded as "yes" to indicate retention.

A set of Non-PNP patients were identified by randomly matching patients using five controls: gender, age group (18-24 years, 25-34 years, 35-49 years, 50+ years), CD4 count (high, medium, low) and HIV "risk factor"/transmission mode (heterosexual contact, MSM, not specified).

5.3.4 DATA ANALYSIS

All data collected were analyzed using SPSS Version 26 analytical software. Exploratory analyses were conducted to better understand and distinguish between the two patient populations – those enrolled (within group) and not enrolled (between group) in the PNP. Categorical outcome variables like viral suppression, retention and engagement were assessed using non-parametric tests. To assess differences within the PNP group, the McNemar test was used and validated using a binomial sign test. To assess differences between the PNP and non-PNP groups, a chi-square test was used given there are only two groups. A higher p-value of 0.10 was used to determine statistical significance given the study's small sample size and past studies with varying impact.

5.4 RESULTS

5.4.1 PARTICIPANTS

Ninety-six (96) African American patients living with HIV enrolled at Palmetto State from January 1, 2016 to December 31, 2018 were matched and assessed for this study. Of study sample, 50.0% (n = 48) were not enrolled in the PNP and 50.0% (n = 48) were enrolled in the PNP during the test period. The average age for each patient group was 46.9 years and 45.6 years, respectively. Both patient groups were predominately male representing 62.5% of each patient group. During the three-year test period, both groups had an average of 7 medical visits (Non-PNP, 7.4 visits; PNP, 6.8 visits). Due to matching, these groups were not significantly different.

5.4.2 VIRAL LOAD SUPPRESSION: WITHIN GROUP (PNP ONLY)

At the initial measurement, 41.7% (n = 20) of PNP patients were virally suppressed, and 50.0% (n = 24) at follow up. An exact McNemar's Test determined there was a significant difference in the proportion of patients that were virally suppressed at the initial and follow up measurements (p = 0.003).

A binominal sign test was done to provide greater context by determining if a greater proportion of PNP patients were virally suppressed compared to those that were not virally suppressed at initial and follow up testing. The binomial test indicated that the proportion of virally suppressed PNP patients at initial testing (0.58) was lower than the expected 0.50 and not significantly different ($p = 0.312$). The proportion of virally suppressed PNP patients at follow up (0.88) was higher than the expected 0.50 and significantly different ($p < 0.001$).

5.4.3 ENGAGEMENT AND RETENTION (PNP ONLY)

At year one (2016) and two (2017) of the study, 77.3% ($n = 37$) and 79.2% ($n=38$) of PNP patients were engaged in care, respectively. By year three (2018), the percentage increased to 87.5% ($n=42$). An exact McNemar's test determined that there were no significant changes in the proportion of patients that were engaged from 2016 to 2017 ($p = 1.00$) and 2017 to 2018 ($p = 0.29$). Without evidence of engagement, there was also no significant change in the proportion of patients that were retained from 2016 to 2018 ($p = 0.18$).

Again, a binominal sign test was done to determine if a greater proportion of PNP patients were engaged over three years and retained over two. The binomial test indicated that the proportion of engaged PNP patients in 2016 (0.77), 2017 (0.79), and 2018 (0.88) were higher than the expected 0.50 and significantly different from each year ($p < 0.001$). The proportion of retained PNP patients (0.79) was higher than the expected 0.50 and also significantly different ($p < 0.001$).

5.4.4 VIRAL LOAD SUPPRESSION: BETWEEN GROUPS

At initial measurement, 79.2% ($n = 30$) of Non-PNP patients were virally suppressed, and 81.3% ($n = 34$) at follow up. Based on the results of a chi-square analysis, we can conclude that there were significant differences in viral suppression between Non-PNP and PNP participants at initial measurements ($x^2 = 6.3$; p = 0.012). However, there were no significant differences at follow up (x^2 =0.03; p = 0.87).

5.4.5 ENGAGEMENT AND RETENTION: BETWEEN GROUPS

At year one (2016) and two (2017) of the study, 83.3% (n = 40) and 87.5% (n = 42) of Non-PNP patients were engaged in care. By year three (2018), the percentage increased to 91.7% (n=44). A chi-square determined that there were no significant changes in the proportion of patients between groups that were engaged from 2016 to 2017 ($x^2 = 0.59$; p = 0.44) and 2017 to 2018 ($x^2 = 1.20$; p = 0.27). Without evidence of engagement, there was also no significant change in the proportion of patients between groups that were retained from 2016 to 2018 ($x^2 = 1.20$; p = 0.27).

5.5 DISCUSSION

This study helped to inform if the Peer Navigation Program implemented at a Ryan White clinic is South Carolina was effective. The data analysis suggests that the PNP had some significant effect on viral suppression for patients enrolled in the service. Patients enrolled in the PNP had higher initial viral loads compared to the Non-PNP patient group. However, the service was developed to engage patients that were virally unsuppressed and/or those at high risk of falling out of care. Thus, the disparity between these initial metrics was not alarming.

The PNP was supposed to help these patients improve viral suppression, engagement and retention; however, it only proved to support viral suppression. Based on the binominal sign tests, the proportion of virally suppressed PNP patients grew with each program year. This suggests that patients may benefit from the PNP program if struggling with viral suppression. Moreover, when compared to their Non-PNP counterparts, there was a significant difference at initial testing but not at follow up for PNP patients. This may suggest that the PNP program closed the disparity gap for its enrollees.

There was no significant difference in engagement or retention within the PNP group or between the PNP and Non-PNP groups. The proportion of PNP patients that was engaged and retained increased over the three years of the study period, but there were no significant changes between the years. This pattern was also reflected between the two groups. This may be the result of groups with a high proportion of engaged and retained patients. Each group averaged 81.3% (PNP) and 87.5% (Non-PNP) engagement over the three years. Though critical HIV care metrics, engagement and retention did not prove to be major barriers for each patient groups.

Despite finding nominal objective success, this study contributes to the potential opportunities of Palmetto State. The organization could use this data to review and revise the implementation of the PNP. One may even suggest investigating the purpose of the service via qualitative interviews and focus groups to best understand how viral suppression, engagement and retention could be impacted. Patient perspectives and suggestions could inform how the service should be modified to best meet or continue to support their needs while significantly impact their health outcomes.

5.5.1 LIMITATIONS

A significant number of patients were ineligible due to incomplete medical records. The missing data could impact the presented results thereby affecting the impending conclusions. Also, the purpose and structure of the PNP changed during the test period and could have shifted how patients perceive and engage in the service.

Lastly, this was a small study within a South Carolina-based clinic. Therefore, it is not certain that these findings can be generalized to other practices, regions of the country, or patient populations.

5.6 CONCLUSION

Peer navigation is a growing trend in HIV care to enhance the patient experience and improve patient care outcomes. A multidisciplinary approach to programming that includes the implementation and evaluation team may provide the support needed to identify and bolster program strengths while mitigating barriers.

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CHAPTER 6

A QUALITATIVE STUDY USING THE MODIFIED SOCIAL ECOLOGICAL MODEL TO UNDERSTAND LIFE WITH HIV AND HIV CARE FOR AFRICAN AMERICAN ADULTS LIVING WITH HIV IN THE DEEP SOUTH[2]

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[2] Willis, K.B., Robillard, A., Ingram, L., Spencer, M., and Smallwood, S. To be submitted to *AIDS and Behavior*.

6.1 ABSTRACT

Peer navigation programs have been identified as a potential strategy to promote care engagement and retention for patients living with HIV, although findings are inconsistent. Fifteen African American adults living with HIV and receiving care at a Ryan White clinic in South Carolina, were interviewed to better understand patients' perceptions of a Peer Navigation Program (PNP) and to identify key factors that encourage or discourage participation. The Modified Social Ecological Model, a multi-level HIV care framework informed the patient interview guide and the directed content analysis. Overwhelmingly, participants expressed externalized and internalized stigma about HIV and their HIV diagnoses as factors affecting participation. High quality comprehensive HIV care and HIV care providers was described as essential to remaining well. Findings suggest that Peer Navigation Programs should include routine mental health counseling and promote patient socialization. The program must also be clearly introduced at enrollment and the role of the Peer Navigator clarified to differentiate between it and other social support services, like case management.

6.2 INTRODUCTION

The transition of HIV from a fatal disease to a chronic condition requires important disease management considerations and innovative approaches for patient care. Access to routine medical care for chronic disease patients can be challenging and is often coupled with a list of environmental and psychosocial determinants that can exacerbate disease outcomes (McBrien et al, 2018). HIV patients have cited lack of insurance, cost of care, organization and delivery of healthcare, and transportation as significant barriers to accessing care and treatment (Dombrowski et al, 2015; Yehia et al, 2015). HIV also carries a burden of shame and stigma that are counterproductive to effective and sustained treatment (Hutchinson & Dhairyawan, 2018).

Despite medication advancements and technology, African Americans contract, live with, and die because of HIV-related complications at disproportionate rates compared to their White peers. In 2017, 43% of people diagnosed with HIV in the United States were African American, despite the fact that African Americans only represent 13% of the US population (CDC, 2019; US Census Bureau, 2019). These racial disparities have been observed since early in the epidemic, and is particularly evident in the Deep South region of the nation. The Deep South (AL, FL, GA, LA, MS, NC, SC, TN, TX) has the highest HIV diagnosis rate of any other US region (Reif, Belden, Wilcon & McAllaster, 2019). According to the Southern HIV/AIDS Strategy Initiative, African Americans living with HIV in the Deep South account for 53% of HIV diagnoses in the region (Reif, Belden, Wilcon & McAllaster, 2019).

Researchers and practitioners have explored concepts of patient navigation as a viable healthcare strategy for people living with HIV (Gardner et al, 2005). Patient navigation was developed in 1990 to address factors that impact healthcare seeking behaviors of poor Americans living with cancer, like cost (monetary and social), fatalism, traumatic healthcare experiences, and the lack of cultural sensitivity (Freeman, 2012). These barriers to healthcare seeking behavior were used to design and define patient navigation as a newfound strategy that could be used to improve health outcomes for vulnerable populations. Nearly 30 years later, patient navigation continues to be a viable healthcare strategy for chronic disease management that can be applied to HIV disease management (Gerves-Pinquie et al, 2018; Kelly et al, 2015). While research has shown that patient navigation programs (PNP) for people living with chronic diseases can significantly enhance care processes and outcomes, results have been inconsistent in terms of whether these programs are effective at increasing patient retention and viral suppression for people living with HIV (Kelly et al, 2015; Mizuno et al, 2018).

A socioecological view of the most pervasive HIV risk factors connected with the Deep South is used to better understand the region's unique and shared challenges. The Modified Social Ecological Model (MSEM) posed by Baral, Logie, Grosso, Wirtz, and Beyrer (2013) provides an alternative to the standard Social Ecological Model in that it is specific to HIV. The standard theory considers relationships within, between and independent of factors across all levels of a health problem. The levels of influence include: (1) Intrapersonal/Individual Factors, (2) Interpersonal Factors, (3) Institutional and Organizational Factors, (4) Community Factors, and (5) Public Policy Factors (Glanz, 1997). Like the Social Ecological Model, the modified version also consists of five levels: (1) Individual Level, (2) Social and Sexual Networks, (3) Community, (4) Public Policy, and (5) HIV Epidemic Stage (Baral et al, 2013; See Figure 5). Stages one through four are comparable to the traditional model, but the modified model combines institutional and community factors and adds the HIV epidemic as a level to conceptualize the influence of population health on individual behaviors (See Figure 2.3). In addition, the model explains that levels are permeable hence factors can be reflected within multiple levels. Together, these factors give context to the complex and multi-dimensional nature of HIV care and related interventions.

6.2.1 INDIVIDUAL

Individual factors that influence behavior include knowledge, attitude, beliefs and skills. Yakob and Ncama (2016) correlate individual knowledge and/or experience with HIV care and treatment as a precursor to one's own engagement in HIV care. Patients that knew of someone that benefited from HIV treatment or witnessed someone die because of no HIV treatment were more inclined to engage and comply with their own HIV treatment plan (Yakob & Ncama, 2016).

Moreover, patients believe that HIV care and treatment are secondary to other basic necessities like food, shelter, and clothing (Baral, Logie, Grosso, Wirtz & Beyrer, 2013). This is an example of a transferable factor, in that it exists in multiple levels. Social determinants of health, or the conditions in the places where we live, work, and play, are both individual- and community-level factors that can be influenced and should be considered by HIV healthcare centers (CDC, 2019).

6.2.2 SOCIAL AND SEXUAL NETWORKS

According to Baral, et al. (2013), social network factors can include groups of people who are predisposed to risk because of sexual or perinatal exposures as well as family and social networks that offer social support or reinforce protective social norms. Other factors include the ability to disclose one's HIV status, stigma, and shame. As both a social network and individual factor, HIV disclosure is a learned skill. People living with HIV who do not disclose their HIV status are less likely to be medically compliant with their HIV care (Mi et al, 2019). Stigma and shame have been cited as pervasive barriers to HIV testing and care in the Deep South (Reif et al, 2011). The region's conservativism influences HIV stigma among people living with the disease, thereby discouraging behaviors like HIV care and treatment (Rueda et al, 2016; Human Rights Watch, 2011).

Social and sexual networks consider interactions between the individual and other people in his/her/their networks (i.e., family, friends) that may provide social support or create barriers for a specific behavior. Southern conservatism impedes communication about HIV/STI care and treatment between and within social networks.

6.2.3 COMMUNITY

Community factors are the larger, organizational networks, processes, culture and standards that support or discourage behavior. Poverty, racism, medical mistreatment, and again, stigma coupled with religious-based homophobia are community level factors that affect opportunities for HIV care and treatment. Poverty within the Southern African American community has been correlated with poor health outcomes and high STI prevalence (Ahnquist, Wamala, & Lindstrom, 2012; Pellowski, Kalichman, Matthews & Adler, 2013). Southern states have the highest unemployment rates, lowest median income, and highest uninsured rates (Heiman & Artiga, 2016; Napravnik, Eron & McKaig, 2007). Poor communities lack resources and medical access promoting the spread of disease.

Lack of access to essential social determinants of health, such as employment, transportation, housing, and education, compounds the problem resulting in African Americans consistently experiencing poorer health outcomes compared to their White counterparts (Bailey et al, 2017). The Deep South is known for its healthcare deficits and inequities for African Americans as a result of sustained individual and institutional racism (Bailey et al, 2017). Racism in medicine has a long, engrained history in the American South, and has contributed medical mistrust and mistreatment that deters African Americans from seeking essential HIV care or dilutes the trust needed to adhere to a prescribed HIV care regimen. Even recent studies confirm that centuries-old racial misconceptions still influence present-day care and healthcare outcomes for African Americans (Hoffman, et al., 2016).

6.2.4 PUBLIC POLICY

Public policy factors include content and implementation of policies that promote or decrease HIV risk (Baral, et al., 2013). Stigma is a consistent thread across all levels of the model that is exacerbated by religious-based homophobia. Homophobia in SC is reflected within the public policy level of the MSEM in that it has been embedded within policies impacting sexual health education. SC is one of seven states that has a law prohibiting discussions about homosexuality in classrooms, except when discussing sexually transmitted infections (*Comprehensive Health Education Act,* 1988). Stigmatizing conversations about this lifestyle limit opportunities for healthy dialogue about HIV risk reduction behaviors, testing, and the importance of consistent HIV care.

Healthcare access is vital to HIV viral suppression and health maintenance, and health insurance is typically the key to access. All of the Deep South states, except for Louisiana, opted not to expand Medicaid (Kaiser Family Foundation, 2016). Uninsured HIV patients are left to investigate and navigate vast and varying healthcare systems and may be required to pay expensive medical bills before care is rendered. In spite of a federal mandate requiring access to quality care for people living with HIV regardless of insurance status or socioeconomic status (HRSA, 2019), both funding and the number of HIV medical providers in Southern states is disproportionate in contrast to other U.S. regions (Gilman et al, 2016).

6.2.5 HIV EPIDEMIC STAGE

The Deep South has the highest rate and number of people diagnosed with HIV and AIDS of any other US region. Like its HIV rates, the Deep South also has the highest rates of sexually transmitted infections (STIs) compared to any other US region (Reif et al, 2016). STIs have a direct correlation to risk of HIV transmission (Cohen, 2012). High regional rates of disease, as factors in the HIV Epidemic stage of the MSEM, play an important role in determining risk for HIV and implications for care and treatment.

The MSEM is itself useful in understanding the root causes and multiple levels of influence on HIV care and treatment. Strategies to respond to these multi-layered factors are needed, and patient navigation has been identified as a potential option. The purpose of this study is to understand the factors associated with PNP participation among African-American adults living with HIV. This qualitative study was guided by the following research questions: (1) What are patients' perceptions of the PNP?; (2) What factors encourage participation in the PNP?; and (3) What factors discourage participation in the PNP?

6.3 METHODS

6.3.1 STUDY DESIGN

This qualitative study sought to understand participation in a PNP among African American adult patients living with HIV in the Deep South as part of a larger study using a mixed methods convergent triangulation design. The qualitative study explored the contextual factors that influence program participation using the MSEM as a sensitizing framework. African American patients enrolled (N=6) and not enrolled (N=9) in the PNP from January 2016 to December 2018 were interviewed. The goal was to better understand the characteristics of an effective PNP and the social and physical barriers to PNP participation from an ecological perspective.

6.3.2 STUDY SETTING AND PARTICIPANTS

Palmetto State HIV Center, a pseudonym used to protect the identity of the center and its patients, is a federally funded outpatient clinic in coastal South Carolina for people living with HIV or at high risk for HIV acquisition. The Center offers a multidisciplinary approach to patient care providing onsite access to a medical team, social workers, mental health counseling, a pharmacy, food pantry, housing assistance and a list of other supplemental services. The center serves over 950 patients (HIV, n = 826; Non-HIV, n = 142) from seven counties in the state.

Of the 800 patients living with HIV and enrolled at Palmetto State from January 1, 2016 to December 31, 2018, 64.6% (n=571) were African American. Of these, 15.5% were enrolled in the PNP during the test period (n=124). For the qualitative portion of the study, fifteen (15) patients who were currently enrolled at Palmetto State agreed to participate. A little over half of interview participants were male (53%), and ages ranged from 22 to 70 years-old. Sixty percent (60%) of the sample were not married, and 100% were insured via Medicare/Medicaid (53%) or private insurance (47%). Moreover, 47% were diagnosed with AIDS. Participant demographics are represented in Table 3.4.

6.3.3 DATA COLLECTION

Prospective participants (patients) were invited to participate in an interview via contact by his/her/their respective case manager. However, this proved to be ineffective. Patients did not respond to email invitations and referrals by case managers were minimal (less than 5) after three weeks of recruitment. Moreover, the hospital system was forced to close offices and significantly reduce patient visits due to COVID-19. All case managers were required to work from home and patient interaction was reduced to phone and video calls. As a result, the center's receptionist was enlisted to assist with patient recruitment. She was still reporting to the office every day despite the COVID-19 restrictions and had more opportunities to engage patients.

A script and recruitment flyer were provided to explain the study to solicit patient participation. The script was comparable to the email that was sent to prospective participants. The script and email detailed the purpose of the study, risks and benefits of participation, incentive for participation, and that participation was voluntary and would be kept confidential. The interview guide was conceptualized using the MSEM. Patients were asked to discuss their experience living with HIV, supports and barriers to remaining in care, and experience (if any) with the Center's PNP. If the patient was not enrolled in the PNP, they were asked for suggested characteristics of an effective PNP. Separate guides were used based on whether participants were enrolled or not enrolled in the PNP. The study protocol and all supplemental materials were approved by the University of South Carolina – Columbia Institutional Review Board and the study site's Institutional Review Board.

Individual in-depth interviews with patients were conducted by an independent consultant to encourage honesty and transparency. This person was unknown to patients and held professional expertise in public health research. All interviews were conducted by phone due to COVID-19 social distancing requirements. Zoom and WebEx was preferred but proved to have varying success related to connectivity, making the phone the most reliable mode of communication. Interviews were recorded using a digital voice recorder and transcribed using Temi, an online transcription service. The interviews lasted approximately 30 minutes and participants were given a $25 VISA gift card for their participation.

6.3.4 DATA ANALYSIS

All interviews were electronically transcribed from the audio recording. Transcripts were reviewed for accuracy by simultaneously reading the transcript and listening to the recording. A directed content analysis of transcribed data was conducted using pre-established themes based on the interview guide and emergent themes that arose organically from the interviews. Selected quotes are presented to illustrate the themes, and investigator triangulation was used to validate findings (Carter et al, 2014). Codes were outlined, defined and discussed between two coders. Disagreements were discussed and appropriately reconciled.

6.4 RESULTS

This study revealed 12 themes organized according to the five levels of the MSEM. Findings highlight pervasive risk factors associated with HIV care in the Deep South and the region’s unique challenges. Each theme is discussed in greater detail and corroborated with supporting significant quotes.

Table 4.1. Qualitative Themes by MSEM Level

MSEM Level	Themes
Individual	Mental and Emotional Responses to Living with HIV Remaining Healthy While Living with HIV Confidentiality and Protecting One’s Status
Social and Sexual Networks	Social Support from Family and Friends Emotionally Protective Factors for Self and Social Networks
Community	Limited Outlets for HIV Health Information Social Determinants of Health and HIV Care African American Cultural Norms in Response to HIV Role of the Peer Navigation Program Recruitment Recommendations
Public Policy	Quality and Accessibility of HIV Care
HIV Epidemic Stage	Knowledge and Awareness of Regional HIV and STI Rates Response to COVID-19 While Living with HIV

6.4.1 INDIVIDUAL LEVEL

6.4.1.1 Mental and Emotional Responses to Living With HIV. Patients expressed varying levels of intrapersonal mental and emotional responses to living with HIV. Responses falling within this theme were rich and ranged from embarrassment/shame/self-blame, to fear (of disclosure/of death), loneliness, depression, and overwhelming stigma. As a male PNP patient described: “There's a lot of shame and alot of stigma and so a lot of hiding which also leads to not being compliant.” (Male participant, PNP, HIV positive since 1996).

As a byproduct of internalized shame, some patients also discussed battles with depression. One participant described feelings of depression upon diagnosis that led to suicide attempts and substance use that compromised care.

> “Well, it's better now than when I was first diagnosed. I was depressed. And I ended up probably some suicidal suicide attempts. I also I started using drugs. You know, I had some issues with that and I've never had his counseling or anything. So with lot of the underlying issues of sexual abuse as a child and stuff like that, so that they got all of that correct.” (Male participant, Non-PNP, HIV positive since 2007)

Another male patient characterized living with HIV as “a sticky situation” that made things more difficult. He later added that

> “It kind of ebbs and flow. Sometimes you have a good day, some days you're having bad days, it's, uh, it can be very depressing, and it can kind of, would take you some time, but you just get a bunch of, just can't live there.” (Male participant, Non-PNP, HIV positive since 1998)

Also closely linked to stigma was a fear of disclosure, and many patients discussed this fear and the difficulty in telling family. A male participant said of this fear, “My family don't know, my friends don't know. It's kind of hard of me dealing with it on my own until I get to that comfortable place to reach out to let my loved ones know.” (Male participant, Non-PNP, HIV positive since 2018) A female patient and mother said: “It's not the easiest thing to tell a family member. Some family members take it the same way and don't want to be around you.” (Female participant, PNP, HIV positive since 2011).

Although most mental and emotional responses were negative, five patients did express acceptance or coming to terms with their diagnosis. A male participant described his HIV diagnosis as “a second chance at life” (Male participant, Non-PNP, HIV positive since 2018). Another gave an even more impassioned response, expressing that she proactively shared her diagnosis.

> “I'm a loud mouth and I told everybody before everybody could tell. I did not have a problem with it. I said I want y'all to understand this: I do not have AIDS. I am HIV positive. I said, ‘If you don't understand what I'm saying to you, look it up!’” (Female participant, PNP, HIV positive since 2000)

6.4.1.2 Remaining Healthy While Living with HIV. Patients reported numerous strategies to become and remain healthy while living with HIV. Several discussed medication adherence as an important aspect of care. Patients that knew of someone that benefited from HIV treatment were more inclined to engage and comply with their own HIV treatment plan. A female patient used her friend’s experience with a HIV as a motivator to remain in care: “I had a friend that also has HIV and she was just really there for me” (Female participant, Non-PNP, HIV positive since 2002).

Moreover, patients relied heavily on education about HIV to better understand how to remain healthy. A female patient expressed how she journeyed to acceptance through building her knowledge of the disease:

> “I'd say it's a hard pill to swallow. I'm dealing with it but it's hard to accept it. Slowly but surely learning to deal with it, learning to take my medicine like I'm supposed to. It's nothing serious as long as I'm taking my

> medicine, so it doesn't turn into AIDS.” (Female participant, PNP, HIV positive since 2011).

Most patients also advocated for taking medication as prescribed and attending all medical appointments. Another discussed the importance of “positive thoughts.” As one patient stated, HIV “is not a death sentence, but it can be.”

6.4.1.3 Confidentiality and Protecting One’s Status. Confidentiality and discretion continue to be key for people living with HIV. Though some shared with others proactively, many still struggled with sharing their HIV status. Patients recalled sharing with close family members first or only discussing their status within the confines of the medical center. Two female participants discussed disclosing to their children. One said, “The hardest part was telling my kids. I told my oldest son first. He said, ‘I love you. I'm gonna always be there for you.’ It's not the easiest thing to tell.” (Female participant, PNP, HIV positive since 2011).

Another used counseling to work through the reasons why he was so guarded about his HIV status, or his “secret,” as described by him. Therapy helped him to eventually share with his mother and siblings. Until then, he recalled that he “had not been talking with anybody about it other than just the counselor and [his] doctor and the social worker” (Male participant, Non-PNP, HIV positive since 2007).

6.4.2 SOCIAL AND SEXUAL NETWORKS

6.4.2.1 Social Support from Family and Friends. Social and sexual networks consider interactions between the individual and other people in his/her/their networks (i.e., family, friends) that may provide social support or create barriers for a specific behavior. Sources of social support included family, friends, church members, and coworkers. Patients expressed numerous ways that family and friends supported and discouraged HIV care. A male patient relied on the love he has for his nieces and nephews. He shared, “my nieces and my nephews are my world, so I know that I’ve still got to continue on in life if I want to see them become something in life.” (Male participant, Non-PNP, HIV positive since 2018). Another patient used family and friends to keep him engaged in the positive aspects of life and less focused on “the worries.”

Yet, others had fewer encouraging experiences with family prompting them to remain isolated from familial engagements. A female patient shared her experience at family gatherings. She said that family were “watching [to see] if [she] grabbed somebody else's cup or something like that…some family members are funny about things” (Female participant, PNP, HIV positive since 1998). Subsequently, she did not feel welcomed and opted not to attend family gatherings. Not only does this example showcase isolation from familial social support, it also highlights the stigma experienced from her family. Others indicated quite plainly that they had no social support network, with one patient saying, “I just don't like talking about my problems, so I just keep them all to myself” (Female participant, PNP, HIV positive since 1998).

While there was little discussion regarding sexual networks except for concerns about transmitting the virus, discussion did highlight the benefit of social networks and the sense of belonging and peer support they can bring. Two interviewees that have been living with HIV for over ten years but were not enrolled in the PNP wanted to provide this type of support for newly diagnosed patients. One female patient was interested but allowed potential backlash and shame to stop her from volunteering. She said:

> “I need courage and what I mean by that is… I would like to help people come along. But yet, I don't want people saying, you know, she got this, she got this. Let's get from by [away from] her.” (Female participant, Non-PNP, HIV positive since 2009)

The other suggested a resurgence of the women’s counseling group facilitated by the Peer Navigators: “I suggest that the program keep up with people, see what's going on, what people really need and try to get the woman group counseling back up because that's something you really do need” (Female participant, PNP, HIV positive since 1998).

6.4.2.2 Emotionally Protective Factors for Self and Social Networks: Self-Reliance and Delayed Disclosure. Several patients said they had no need to rely on others in their social networks, instead relying on themselves, e.g., “That part of my life is my own business.” This seemed to be a way to protect themselves from emotional harm that might be caused by others in their social networks. One male participant talked about HIV care as having, “a sense of my own self-control. My health, my life” (Male participant, Non-PNP, HIV positive since 2008). Several described themselves as people who “kept to themselves” or “prayed a lot.” Self-reliance was captured in this quote:

> “It never bothered me. When I was first diagnosed, I'm not a person that dwells on stuff and let it kill me. I mean, it was something I had to deal with, so I dealt with it. I asked the doctor, what do I do? And she said, well, these are the meds, this is what you do. And I did what she said and I'm fine.” (Female participant, PNP, HIV positive since 2000)

For some, however, loneliness was a by-product of that independence. One participant said, “it can be lonely cause I keep it to myself. It'll be only the program, the medical center, that will be my only outlet” (Male participant, Non-PNP, HIV positive since 2008). When asked about their social support, several participants, both in and out of the PNP, described only relationships with staff at the clinic only, in the absence of support from their own social networks.

HIV disclosure is a transferable factor that operates at both the individual level as well as the social network level. Disclosure is an important consideration because it increases the likelihood of medical compliance for people living with HIV. Compared to the shame and embarrassment discussed at the individual level, patients also expressed their failure to disclose, or their intention to delay disclosure, as an emotionally protective strategy. One participant discussed the delay in connection with time needed to ready oneself to share the news with family. Another patient shared:

> “I told my family later on down the line when I started to take my health more seriously. Once I found out that I had [HIV], I thought that was going to be the end. I would eventually get sick and I was going to die. So, I didn't want to involve my family that much because I didn't want them to get involved in that aspect of it. But as I started getting better and started taking my meds and taking my health seriously I told them about it” (Male participant, PNP, HIV positive since 2016).

6.4.3 COMMUNITY

6.4.3.1 Limited Outlets for HIV Health Information. Community factors are the larger, organizational networks, processes, culture and standards that support or discourage behavior. Poverty, racism, medical mistreatment, and again, stigma coupled with religious-based homophobia and conservatism are community level factors that affect opportunities for HIV care and treatment. Findings from this study suggest that the social conservatism of the Deep South poses a unique barrier to sexual healthcare for many patients living with HIV. An interviewee that relocated from New York felt like it was “hard to find programs” in South Carolina and there were limited outlets for information. In the North, he said that “there were signs in the streets, there were places to go” (Male participant, Non-PNP, HIV positive since 2008).

South Carolina is one of seven states that has a law prohibiting discussions about homosexuality in classrooms, except when discussing sexually transmitted infections (Comprehensive Health Education Act, 1988). Moreover, the Comprehensive Health Education Act has not been amended since 1988 despite 40% of South Carolina students reporting that they have had sex at least once (Comprehensive Health Education Act, 1988; SC Department of Education, 2020). Moreover, over 77% had never been tested for HIV (SC Department of Education, 2020). This perpetuates the myth, and related stigma, that HIV is only linked to a homosexual lifestyle and reinforces the idea that education about sexual relationships between same sex couples are inappropriate. In fact, a patient compared having HIV in South Carolina to coming out as gay: “It's like being gay and coming out and then you get this hate crime. I think that's what most people are afraid of that have HIV - a hate crime” (Female participant, PNP, HIV positive since 2000).

6.4.3.2 Social Determinants of Health and HIV Care. Poor communities lack resources and medical access promoting the spread of disease. Lack of access to essential social determinants of health like employment, transportation, housing and education compounds the problem resulting in African Americans consistently experiencing poor health outcomes. When asked about barriers to care for people living with HIV and community outreach, a patient passionately shared her beliefs that the mentality of the residents in her apartment complex reflected a severe lack of education and did not compare to a more affluent and White community. "I don't live on The Battery. You know, I live in an apartment complex with a bunch of [N-word expletive]. You understand me?" (Female participant, Non-PNP, HIV positive since 2009). This "ignorance," as she put it, stood in the way of accessing care. Likewise, limited funds and transportation were also cited as community level barriers to care:

> "My doctors and them said I had to make these appointments but at the end of the day, my doctors weren't paying my bills - I was paying my bills. If it came down to it, I always picked my job. I always picked work. I picked other things instead of putting my health first because I really didn't have any other options." (Male participant, PNP, HIV positive since 2016)

6.4.3.3 African American Cultural Norms in Response to HIV. HIV in the African American community continues to be a complex discussion for practitioners and researchers due to the shame and stigma often associated with the disease. A male participant spoke to this cultural norm and the associated shame directly saying,

> "Some people are embarrassed, you know, I know I was at one point, it's a very, it's a very sticky situation. It doesn't have the negatives, uh, connotations that had had before, but in the African American community it's, eh, it's a, it's not a, it's not a positive topic. Right. Okay. That can make things a little difficult." (Male participant, Non-PNP, HIV positive since 1998)

As previously noted, shame and stigma can create significant barriers to education, prevention and care. Another male participant shared this opinion with an emphasis on the Black community's connection to religion as a catalyst for these perceptions and perpetuation of the stigma.

> "In the black community, you know, you know, be at church. You know what I mean? There's always that old mentality that we have with sweeping things under the rug and you know, we know about it, but we don't." (Male participant, Non-PNP, HIV positive since 2007)

6.4.3.4 Role of the Peer Navigation Program: Recruitment. Despite the Peer Navigation Program's primary objective to engage patients outside of their case manager and clinician to provide an added layer of social support, eight of the fifteen patients interviewed had not heard of the program. In fact, four of the eight were indeed enrolled and noted engagements with the center's Peer Navigators. When asked if they had ever heard about the Peer Navigation Program, these participants responded with statements like "I don't remember. It's been a minute." or "I think I know it, but it's been a while." Moreover, this sentiment was consistent among these participants despite their varying PNP participation, gender, and enrollment years (1998 to 2018).

However, when given details about the program and the names of the Peer Navigators, participants in the PNP immediately knew what it was, while those not in the PNP conflated their knowledge of the program as a part of their full experience at the center. This made it difficult to parse and decipher attitudes specifically about the PNP outside of the Palmetto State Center. For example, one of the participants who claimed to be in the program said, "Yes, yes, yes, yes. That's a good program. I mean, yeah, I've been through it. I mean, I, I understand what you're saying now" (Male participant, Non-PNP, HIV positive since 2008). Yet, he was not a PNP participant. Another male patient shared that he liked:

> "How relaxed the environment is. Like everyone knows each other, not *know* each other, but it's always a friendly environment. Anything that's going on, they all walk around with smiles on their faces." (Male participant, PNP, HIV positive since 2016)

Yet, there are only two Peer Navigators and only one is present onsite at any given time.

Those participating in the PNP heard about it from their case managers and one purported that the program was developed because

> "each case workers and case managers, they getting overloaded. So they be like you know, like just almost like a factory like, you know, get them in, get 'em out, get 'em in and get them out,…So I think that's how they put this program in there to bridge a gap so they, you know, could be more personal." (Male participant, PNP, HIV positive since 1996)

Those that opted not to participate cited barriers like time conflicts with work, not having enough information about the program, not needing additional social support or disinterest in connecting with a HIV peer. A female participant shared that she would rather connect with a leader within the center.

> "But I don't want to have one on one with somebody with HIV. I would like to have one on one with somebody with authority. You know…I don't

> need nobody to teach me something and we both walking in the same boat." (Female participant, Non-PNP, HIV positive since 2009)

6.4.3.5 Role of the Peer Navigation Program: Recommendations. Regardless of their participation in the PNP, interviewees offered recommendations for the service and delivery of the PNP. A Non-PNP female suggested that Peer Navigators first gauge comfort level of the patients that they seek to help to better understand their boundaries.

> "I think for one, first things first, you know, getting to find out how comfortable the person, the people are with sharing their experiences. I think that's the first step. You know, before you can ask them to do anything or whatever the case may be, you need to find out where their mind stands or how comfortable they would be. You know, because to me that's overstepping certain people's boundaries." (Female participant, Non-PNP, HIV positive since 2009)

Others suggested non-traditional hours and locations to better accommodate those in remote areas or with financial barriers to care. He said, "I know it's not all about making people feel more comfortable other than trying to get you the help you need, but expand locations [to] more secluded areas and close to low income areas and such, too" (Male participant, Non-PNP, HIV positive since 2008).

More educational opportunities and general HIV awareness were also noted. Two participants, both in the PNP, referenced the need for more information about HIV in the community for people living with HIV and those who are not. The female that was diagnosed in 2000 said, "more education would be good. To educate the people that don't have it, that don't know, that think if you come in the house or you hugged them, that you might be contagious."

Surprisingly, there were only two Black male participants that presented an argument about diversity. One felt conflicted and annoyed with the lack of diversity within the center. He said:

> "[Name of Peer Navigator] is a really nice white man. He's a very nice white man. The majority from my viewpoint of the clients that come into the center are black men, [but] there's no representative, no representation. You know, you go in there and [he's] great, but I don't think a lot of people will talk to [him] like they need to talk to him. Maybe the women would, I don't know." (Male participants, Non-PNP, HIV positive since 1996)

To that sentiment, 65% of the center's patients are African American yet both of the Peer Navigators are White. He went on to share his belief that this is a real barrier to getting tested and receiving treatment. Rather than calling out racism, the other male participant described this Southern cultural norm as "rude people that've been rais[ed] traditionally".

6.4.4 PUBLIC POLICY

6.4.4.1 Quality and Accessibility of HIV Care. Other public policy factors, or the local, state and federal laws and policies that regulate behavior, most relevant to HIV care and treatment in the South are Medicaid expansion and the Ryan White Care Act. Healthcare access is vital to HIV viral suppression and health maintenance, and health insurance is typically the key to access. Patients overwhelming expressed their satisfaction with services provided by the center, and often cited specific staff as essential in their journey living with HIV. One of the center's senior nurses passed away in March 2020. A female patient expressed her gratitude and grief:

> "My experience with [name of clinic]RWWC, God rest Donna's soul. She's been my nurse since I was in the program and I miss her so much. Everyone gives moral support and has been patient with me so I try to do what I'm supposed to do to keep things under control." (Female participant, PNP, HIV positive since 2011).

Patients also discussed specific characteristics that they appreciated at Palmetto State, e.g., the "whole-person" approach they employed. A few shared that their HIV case manager assisted with treatment and resources outside of their HIV care to include substance abuse and domestic violence. A male participant disclosed that he battled with substance abuse and the center assisted with treatment: "They made sure I got treatment for the substance abuse before I got treatment for anything else, which was very important…They basically just took care of everything. I didn't have to think about a lot of stuff" (Male participant, PNP, HIV positive since 1996). Another patient shared the same sentiment saying, "They let you bring everything to the table, whether you're having problems at home, they want to know everything, you know, and they help you out with everything" (Female participant, Non-PNP, HIV positive since 2009). She later summarized the comprehensive and compassionate care as "they show you that you can trust them 100%."

Participants also recognized and appreciated the accessibility of the Center, noting with gratitude that the Center exists and that "if it wasn't for [the Center], who knows where me or half of everyone in Charleston would have been who have HIV" (Male participant, PNP, HIV positive since 2016)? Another example that highlighted the accessibility of care came from a veteran who left the Center to seek care through resources available to veterans but had to return to the Center after receiving virtually no assistance.

> "I switch over to the VA and start, you know, start care. I came over there and it didn't really work out… for the last eight months, I switched over there. I've never seen anyone, I haven't had anything. So I called my case manager to get back into the program here at the wellness center." (Male participant, Non-PNP, HIV positive since 2007)

6.4.5 HIV EPIDEMIC STAGE

6.4.5.1 Knowledge and Awareness of Regional HIV and STI Rates. The Deep South has the highest rate and number of people diagnosed with HIV and AIDS of any other US region. Like its HIV rates, the Deep South also has the highest rates of sexually transmitted infections (STIs) compared to any other US region (Reif et al, 2016). STIs have a direct correlation to risk of HIV transmission (Cohen, 2012). Relevant statistics regarding the high rates of HIV and STIs in the South were shared with interviewees, and they were asked for their thoughts and opinions about the South as the new HIV/STI epicenter. Patients commonly mentioned the lack of education as a prime contributor to the escalating rates. One interviewee called South Carolina "the less educated of all of the [states]” because sex and sexuality are not discussed though there are high rates of sexual activity (Female participant, PNP, HIV positive since 2000).

6.4.5.2 Response to COVID-19 While Living with HIV. However, the emergence of COVID-19 has brought a newfound awareness to infectious diseases and a heightened sense of responsibility for people living with or at high risk for HIV. A female participant was washing her body with bleach until the doctor advised that it was unnecessary and potentially harmful. Yet still, she said,

> “I washed my hands up to my elbows. I'm so, so you know, thinking that if it gets on me because of my [HIV], but then I also need to remember that I am undetected.” (Female participant, Non-PNP, HIV positive since 2011)

With Palmetto State moving to less traditional virtual platforms, patients described the use of texting for regular communication, as well as a virtual visit that an interviewee described as “weird”. One participant also discussed the emotional impact of COVID in this way:

> “I believe that people are not informed. I don't know if it's the government and I don’t even want to get into that, but it is hard to see the amount of people dying every day. And so that affects you, you know” (Male participant, Non-PNP, HIV positive since 2007).

6.5 DISCUSSION

Having been in existence for five years at the Palmetto State HIV Center, there is a need to clearly define and evaluate the program’s limitations, strengths, and opportunities to improve. This information can be used to better understand patient barriers to medical adherence, and strategies and services to address these barriers using a comprehensive framework. The MSEM offers a multilayer lens to consider how HIV programs can best serve patients and address the sociopolitical and environmental factors that influence patient behavior.

Internalized stigma and its emotional by-products seemed to be most severe at first diagnosis, but were present for some long after—serving as a barrier to care. When asked about their emotional responses at the time of their HIV diagnosis, most patients discussed an initial struggle with acceptance and disclosure. Conversations about depression, fear and self-isolation were common among participants. Stigma was also a thread observed across the patient population and at multiple levels. Stigma at the community level was fostered by a lack of education, cultural norms, social determinants of health, and restrictive policies, all of which pose barriers access to HIV care providers in the South.

The South – especially the Deep South – has conservative laws that discriminate against or create impermeable barriers for people living with HIV, namely the Comprehensive Health Education Act and South Carolina's HIV criminalization laws (CHEA, 1988; The Center for HIV Law and Policy, 2020). These laws also perpetuate the external shame and stigma associated with the disease while stoking the internalized stigma and shame that many patients experience. Conservative federal and state policies determine local access to general sexual health information and reputable HIV services (Reif et al, 2016). Adapting the policy so that it is medically accurate and unbiased could begin to reverse the cycle of stigma infused throughout the community and imposed on people living with HIV. Aggressive and persistent advocacy that also demand a reallocation of resources will be required to promote this level of radical cultural change.

Patient navigation in HIV is comparable to traditional case management. It is a hybrid of "advocacy, health education, case management, and social work" conducted by trained professionals or paraprofessionals to support positive health outcomes (Bradford et al, 2007). Similarly, case management is defined as "a range of client-centered services that link clients with healthcare, psychosocial, and other services provided by trained professionals (TargetHIV, 2019)." Case management is reserved for trained professionals, and patient navigation can be facilitated by lay or trained professionals. Nonetheless, both strategies are used to reduce barriers to care and are often used interchangeably. In fact, the data revealed that participants enrolled in the PNP sometimes struggled when differentiating between whether they were a part of the program or not. During interviews, participants were reminded about their enrollment status and asked to clarify their responses to ensure that the subject remained consistent. This suggests that patients conflate the experiences with the case manager and Peer Navigator. The consistent conflation from interviewees that were enrolled and not enrolled in the PNP also suggests that clarity of roles upon enrollment could be improved. While the PNP was not explicitly stated or implied as the sole motivating factor for engagement or retention in care, all patients expressed overall satisfaction with their experience at the Palmetto State Center based on factors that foster care engagement and retention, like a friendly staff, quality service, and a welcoming environment.

The present study's findings confirmed several strengths about the center's overall comprehensive approach to care. First, the quality of comprehensive HIV care is essential to retention. Participants discussed trustworthy relationships with staff and their medical providers as important characteristics of any HIV care program. It is in these relationships that they learn how HIV works within the body and how to live well with HIV.

Participants also cited the importance of comprehensive care, or staff that are concerned with their full life – not just their immune health. This all-inclusive care is the foundation for Ryan White Care Act. The Health Resources and Services Administration (HRSA) understands the importance of patient-centered care and how one’s social determinants can affect their health outcomes. Hence, Ryan White programs are encouraged to use grant funding to support patients’ social determinants like housing, food, transportation, health insurance and mental health (HRSA, 2019). Difficulties with any of these situations or conditions places a barrier to accesses and maintain HIV care. If a patient must decide between food and a medication co-pay or rent and health insurance, most would opt for the former to maintain their basic human needs of food and shelter.

Because patients felt connected and accountable to their HIV care providers, they were also quite knowledgeable about how to remain well while living with HIV. Medical appointments at the Palmetto State HIV Center are extended from the traditional 15- or 30-minute time slots to 30- or 60-minutse to allow more time for patient questions, health education, and rapport building. Time to learn about the disease, essential lab tests, and how to interpret results create a sense of security and hope and shows patients that they have control to manage the disease. Participants cited this as motivators to taking their medication and remaining compliant with their medical appointments.

In contrast, several opportunities were learned from interviews. First, center patients should be referred to a therapist upon enrollment to develop a comprehensive care plan that will promote and strengthen mental health and wellness Patients consistently struggled emotionally with their HIV diagnosis, at least at first diagnosis. Making therapy a routine practice for all could destigmatize mental health care for African American patients. Research has noted the reluctance of African Americans to seek counseling or psychiatric care due to familial or community-wide stigma (Kreps, 2017). If established as a part of the program for everyone, administrators could mask care as a standard service for all without bringing attention to those who need it most.

Administrators should also consider the inclusion of diverse Peer Navigators. There are only two Peer Navigators at the Center, and both are White. About two-thirds of the Center's patients are African American. Research has proven that race concordance between patient and provider yields better health outcomes (Shen et al, 2018). This does not mean that African American patients cannot thrive under the care of a White or non-African American provider, case manager, or Peer Navigator. Yet, findings suggest that it empowers participants in healthcare spaces. Patients expressed feeling more accountable and culturally-connected to caretakers of their race or ethnicity (Shen et al, 2018).

Lastly, the Center should consider opportunities for patients to socially engage with others living with the disease. Unlike a traditional medical practice, the Palmetto State HIV Center can host patient-centered social events during the holidays and re-ignite patient support group meetings. Patients expressed that social support is a motivator to staying well and in care. Although not all expressed a desire for this, paired or group events can encourage socialization and be used to strategically promote the overall wellness goals of the healthcare center.

This research was conducted during the onset and initial peak of the COVID-19 pandemic in the United States. Fortunately, none of the patients interviewed were diagnosed with coronavirus or have been significantly impacted by the virus. At the time of this article, there were only five confirmed COVID-19 patients of the center. Supplemental federal funding has been provided to support patients during pandemic as many were impacted financially by mandated business closings and furloughs.

6.6 LIMITATIONS

COVID-19 posed the most glaring limitation to this research study. The sudden impact of this novel virus required unintended modifications to best adhere to the safety guidelines of the Palmetto State HIV Center, South Carolina, and federal agencies like HRSA and the CDC. Patients were to be recruited and interviewed onsite as they arrived for medical or case management appointments. Palmetto State moved at least 80% of its visits to virtual platforms, so patients were recruited by email, phone, and sporadically as they arrived for lab appointments. Interviews were conducted by phone given varying internet access and connectivity.

Additionally, the sample size of 15 may not reflect the perspectives and opinions of the larger African American patient population. Those who participated may have been motivated by a desire to give feedback on the program or they may represent more engaged patients. Selection bias is common, and is noted as a potential limitation in addition to the smaller than expected sample size. While we hoped for a slightly more participants, saturation was reached for the major themes related to HIV care.

6.7 CONCLUSION

Peer navigation in HIV care was designed to enhance the patient experience and improve patient care outcomes. For the practice to be successfully implemented, patients implied a need for role clarity between peers and case managers and explicitly cited greater attention to social connections between patients, more educational opportunities, mental health referrals, diversity among peers, greater accessibility outside of traditional business hours and locations and continued comprehensive, patient-centered care. Building the Peer Navigation Program as a component of the center’s mental and behavioral health programming may provide an innovative approach to these issues.

We learned that a collaborative, comprehensive structure is valued by patients regardless of their participation in the PNP. Chugh et al (2009) recognized that in the midst of “heightened vulnerability”, patients often miss vital healthcare information despite an increased request for patients to be more involved in their care and limited resources to assist with that self-care. Repetition in healthcare information and resources aids this deficit (Chugh et al, 2009). Upon enrollment into a Ryan White program, patients should be introduced to the PNP from their case manager and also (1) meet the on-duty Peer and (2) receive written information about the program. This would allow an opportunity to hear about the program three times and capture each learning style – auditory, visual, and kinesthetic. Additionally, administrators should consider housing the PNP within its mental health department or strategically pairing the two services. Collaboration between the mental health staff and the Peer Navigators could provide the added social and mental health support that patients discussed as a personal deficit. Developing this type of collaborative hand-off between staff also fosters care continuity and communal care teams, important antecedents to high quality healthcare and positive health outcomes.

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CHAPTER 7

DISCUSSION

7.1 INTRODUCTION

Caring for patients that are clinically high-risk and socially complex is a persistent conundrum for many medical and public health professionals. Peer Navigation presents an opportunity to bridge the assets of case management, social work, patient advocacy and peer support for these vulnerable patients. Yet still, this promising patient support intervention has variable outcomes that require additional research and evaluation especially for patients living with HIV.

HIV is a chronic condition that is often accentuated with environmental and psychosocial factors that impact access to and retention in care. Since the discovery of antiretrovirals in 1987, researchers and practitioners have worked both independently and collaboratively to develop clinical and social interventions to encourage sustained wellness for people living with HIV (USFDA, 2018). Medication adherence and care compliance are essential components to viral suppression, increased life expectancy, and HIV prevention for their sexual partners (Meissner, 2018).

Despite these advancements in HIV knowledge and care, African Americans living with HIV continue to contract, live with and die as significantly higher rates compared to their White peers (CDC, 2018). African American women, youth (ages 13

24), and MSM have been identified as priority populations struggling with the disease (CDC, 2018). A closer look reveals that geography compounds this health disparity. African Americans in the Deep South living with HIV represent over half of HIV diagnoses in that region (Reif, et al, 2019).

The study sought to evaluate how one healthcare center in South Carolina chose to improve the clinical outcomes of its African American patients. Palmetto State HIV Center is a federally funded, comprehensive sexual health center that cares for nearly 1,000 patients. In 2014, they initiated a Peer Navigation Program (PNP) to address disparities in viral suppression, care engagement and care retention for patients that were virally unsuppressed. The PNP has been fully operational for five years at Palmetto State, but this is its first outcome evaluation. This study focused on African American patients enrolled in the program given consistent statistical data implicating the population as susceptible for increased adverse health risks. The specific aims for this study were:

> **SA1.** To determine the effectiveness of a Peer Navigation Program (PNP) for African American adults living with HIV using the following objective and biological HIV care metrics: patient engagement, care retention, viral load, and achievement of viral suppression; and
>
> **SA2.** To qualitatively assess what factors are associated with PNP participation among African American adults living with HIV.

7.2 SUMMARY OF FINDINGS

The first specific aim was assessed quantitatively, and it was hypothesized that African American PNP participants would have a higher patient engagement rate, higher care retention rate, and lower viral load after PNP participation compared to levels at baseline. Additionally, a greater proportion of African American PNP participants would achieve viral suppression after PNP participation compared to levels at baseline. When compared to their non-PNP counterparts, it was hypothesized that the African American PNP participants would have a higher patient engagement rate, higher care retention rate, and lower viral load after PNP participation compared to African American patients who did not participate in the PNP. A greater proportion of African American PNP patients would achieve viral suppression after PNP participation compared to African American patients who did not participate in the PNP.

Quantitative results suggested one positive outcome and a few potential complementary program strengths. There was a significantly higher proportion of PNP patients that were virally suppressed after engagement in the PNP. Though there was an impact on viral suppression, there was no significant difference in engagement or retention within the PNP group or between the PNP and Non-PNP groups. It is important to note that the PNP was developed for patients that were virally unsuppressed. Typically, these patients require more than average clinical appointments to monitor their disease state. Uncontrolled HIV viremia can cripple the immune system exasperating other existing conditions or diseases or place a patient at increased risk for acquiring additional conditions or diseases (CDC, 2019). For this reason, virally unsuppressed patients would have more than the standard two appointments per year. However, both patient groups averaged more than 80% engagement over the three years. Despite no significant changes, this is a positive finding that may be attributed to characteristics of the Palmetto State HIV Center.

The second specific aim was assessed qualitatively. The goal was to glean information about the patients’ perceptions of the PNP and gain greater insight into which factors encouraged and discouraged participation in the PNP. The Modified Social Ecological Model was used to guide the interviews—allowing for a multi-layered assessment of issues impacting HIV for patients, even as emphasis was placed on patient knowledge and perceptions of the PNP and their decision to enroll or not. However, the qualitative data collected did not answer this aim as intended. Despite facilitating an interview guide with targeted questions about the PNP, majority of patients still reverted in general thoughts and opinions about the HIV center. Moreover, patients seemed to be confused about their participation in the PNP and at times had to be reminded at the beginning of the interview. Further, a notable portion of qualitative patient data focused on factors seemingly unrelated to the PNP, but with foresight, can inform the PNP program. The data provided valuable information that could be used to determine PNP and general HIV care strengths and opportunities for African Americans adults living with HIV at Palmetto State HIV Center. Thus, qualitative results were not disregarded. Instead, significant themes were populated using the Modified Social Ecological Model (MSEM) as a framework in hopes that each level of influence on HIV-related health outcomes could be considered and potentially addressed.

When considered alongside qualitative findings, there were several components from the PNP that promoted medication adherence thereby supporting viral suppression. Patients, both enrolled and not enrolled, expressed feeling connected and accountable to their care providers, and cited extended appointment times to build rapport with their clinical providers. Extended time with providers was essential to learning about the disease and how to interpret routine lab results. Participants explicitly named these as motivators to taking their medication and remaining compliant with their medical appointments.

Patients also appreciated the high-quality care and an emphasis on their full life, not just their clinical needs. HRSA endorses a patient-centered medical home model and encourages its grant recipients to incorporate the fundamental principles of the model. There are five core principles of a patient-centered medical home: comprehensive care, patient-centered approach, coordinated care, accessibility of services, and quality and safety (US DHHS, 2015). These are pillars of the federal Ryan White Care Act. The funding allows healthcare facilities to work outside of traditional healthcare practices to meet the comprehensive needs of its patients.

7.3 IMPLICATIONS FOR PRACTICE

Studies of patient navigation demonstrate variable success for adults living with HIV. Five of the sixteen studies from 2005 to 2019 included in the literature review reported no significant results, and four of these five studies with null findings assessed viral suppression. The remaining studies had varying success. Of note for the quantitative portion of the study presented here, are findings related to success in achieving viral suppression. Bradford et al (2007) assessed structural and belief barriers to care and viral suppression among 437 people living with HIV. They found that those enrolled in the patient navigation group reported a reduction in barriers to care, and there was an increased proportion of patients that were virally suppressed by the end of the 12-month study period. Cunningham et al (2018) also assessed viral suppression of 356 jailed inmates living with HIV who participated in a peer navigation linkage program following their release and found that there was a positive association between patient navigation and viral suppression. For these two studies, those enrolled in the patient navigation program were more likely to be or become virally suppressed. Yet still, none of these studies were exclusive to African American adults living in the South providing limited inferential data for this priority population. The current study builds on existing literature to begin to fill this gap in the literature. Findings show that the PNP is linked to viral suppression.

Qualitative studies have also been used to better understand peer navigation programs, and these have also suggested success, primarily around retention. Cook et al (2018) interviewed 27 patients enrolled in the patient navigation program who described a reduction in barriers to care. My study also incorporated qualitative methods to attempt to understand PNP participation, finding notably that most patients could not necessarily distinguish between the PNP and standard Center care. The use of the MSEM also brought to light issues that could be linked (either positively or adversely) to care related to the multiple levels of influence operating in a patient’s life.

The limited and inconsistent findings from research on peer navigation programs could be a result of the very appeal of patient navigation; it is customizable. Researchers have offered at least three different models that can be employed with shared responsibilities of a traditional HIV case manager, a standard component of most HIV care programs. The first model (a trained layperson that identifies with the population) was used at Palmetto State and there was consistent confusion between the PNP and case management among the patients interviewed for this study (Braun, 2012). Patients had to be reminded of their participation status throughout the interview by specifically using the names of the Peer Navigator and the patient's respective case manager. For instance, rather than asking if the patient was "enrolled in the PNP", the interview began asking, "How often do you connect with [Name of Peer Navigator]?" or "Tell me about your experience with [Name of Peer Navigator]." Information about the patient's enrollment status was available in the electronic medical record and given to the interviewer prior to the call to ensure that the correct interview guide was used. Having the ability to contextualize the data using a mixed methods approach allowed me to conclude that the high-touch care model employed by Palmetto State is more important to patients than who delivers the touch. The PNP and case management staff are seen as one unit and their services are discussed interchangeably.

A clear marketing, recruitment, and communication plan for the PNP may resolve patient confusion. When patients are referred to a peer navigator by his/her case manager or clinical provider, there should be a follow up conversation that outlines the purpose and expectations of the PNP. Patients described and appreciated the center's collaborative approach to care but should be able to differentiate between the agency's services. The blurred lines between peer navigation and case management could be the reason for the variability in past evaluations and this study.

Additionally, the data suggests that the PNP should be coupled with or enhanced by behavioral services, a component that was only mentioned in one previous study (Bradford et al, 2007). PNP and non-PNP patients expressed traumatic experiences with shame, stigma, and depression. Incorporating formal behavioral health counseling by a licensed therapist could help patients unpack the psychosocial emotions that can be triggered by a HIV diagnosis and long-term care of the chronic disease. At the Palmetto

State HIV Center, the behavioral health therapist is located in a different suite outside of the medical clinic away from the case management team. If the peer navigators are supervised by the therapist and moved to that suite, proximity may also support enhanced social support services and clarification of roles and responsibilities.

Lastly, the PNP was perceived by patients as an opportunity to connect with their peers; however, there is a lack of diversity and opportunities to engage socially outside of the clinic. Over 60% of Palmetto State patients are African American yet both Peer Navigators are White. Though this was only mentioned as a point of concern by two patients, research has shown better health outcomes and greater empowerment when patients can connect culturally with their care providers (Shen et al, 2018).

As for social engagement, COVID-19 has gravely restricted social interactions. Palmetto State has reduced its onsite clinical and case management visits by 50%, and now encourages phone or virtual meetings. Moreover, COVID-19 and how it interacts with HIV is still an evolving discovery among researchers and practitioners. Patients expressed a strong interest in more social gatherings to mitigate loneliness and create comradery, but this has been suspended until COVID-19 is better managed – clinically and socially. It is too early to tell the long-term impact COVID will have on PNP and HIV care, but it should be examined.

While the qualitative analysis did not explicitly answer the proposed aim, it did provide contextual information that can be used to give a fuller depiction of living with HIV and receiving care that supports the significant quantitative results found. Also, using the MSEM provides a concrete framework by which significant themes can be strategically addressed by the most appropriate stakeholder at Palmetto State HIV Center.

7.4 RECOMMENDATIONS

Further investigation and research are recommended to fully understand the nuances of the PNP, from patient recruitment to facilitation to patient discharge. A multidisciplinary team of administrators and evaluators should work collaboratively with the peer navigation, case management, and behavioral health teams to fully understand patient needs and how they coincide with the purpose of the PNP. The MSEM provided a clear and concise framework by which the purpose of the PNP can be explored. Patients cited factors from each level of the MSEM model that could be further explored to determine if and how those factors can be addressed, and by whom. As an example, findings that highlighted the mental and emotional health needs of patients serve as an opportunity for the PNP.

Also, it is important that patient records and case notes are routinely updated. Coupled with focus groups and interviews at pre-determined intervals, this comprehensive approach could provide information about the program in real time allowing for comprehensive analysis and quick changes when appropriate. While specific to only one center in South Carolina, findings could be used to inform future Peer Navigation Programs for African American patients living with HIV.

7.5 STRENGTHS AND LIMITATIONS

There were several strengths and limitations throughout this research process. I am an employee of Palmetto State HIV Center and have had an opportunity to witness the changes of the PNP. I was hired within the first six months of the program in December 2014 and indirectly supervise the PNP team. This gives me some authority over how the program operates. Thus, I can review the data with the greater team to influence how best to move forward.

I was also familiar with the two electronic medical records required to retrieve the clinical data for each patient. Each electronic medical record operates differently and can present significant learning curves that may require IT support. However, I was able to easily navigate the two systems as needed making data analysis more efficient. Moreover, the matched design used for the quantitative analysis helped to reduce the effects of confounding variables making data analysis cleaner and clearer.

Despite these advantages, there were limitations that were exasperated by COVID-19. The virus triggered a national lockdown in March 2020 at the height of my data collection process. Teammates and patients were barred from the office until safety guidelines could be developed and dispatched. Patients were to be recruited and interviewed onsite as they arrived for medical or case management appointments. However, within one week, Palmetto State had moved 80% of its visits to virtual platforms and gravely restricted onsite employees. Consequently, patient recruitment was much slower than intended. I had to resort to recruitment help from the front desk receptionist, one of the consistent onsite employees.

Interviews were conducted by phone given internet access and connectivity issues. Non-verbal expressions are just as important as verbal responses, and this element was lost over the phone. The ability to sit in a shared space or to see one another via a teleconferencing platform could have possibly impacted the results of the qualitative data.

Lastly, the sample size of 15 for the qualitative study may not reflect the perspectives and opinions of the larger African American patient population. Those who participated may have been motivated by a desire to give feedback on the program or they may represent more engaged patients. Selection bias is common and is noted as a potential limitation in addition to the smaller than expected sample size. While we hoped for a slightly more participants, saturation was reached for the major themes related to HIV care.

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APPENDIX A

OVERVIEW OF PATIENT NAVIGATION AND HIV RESEARCH

Table A.1. Patient Navigation and HIV Research by Author and Year

Year	First Author	Measures	Population	Findings
2005	Gardner	Retention	N = 273 Newly Diagnosed PLWH Standard of Care Case Management	Increased retention for case managed patients
2006	Wohl	Viral Suppression, CD4	N = 250 PLWH DAART IACM Standard of Care	No significant findings
2007	Bradford	Structural and Belief Barriers to Care, Viral Suppression	N = 437 PLWH - Standard of Care - Patient Navigation HRSA-endorsed study	Reduction in barriers and viral suppression for patients with a patient navigator
2011	Wohl	Viral Suppression, CD4	N = 104 Inmates LWH Standard of Care Case Management	No significant results

Year	First Author	Measures	Population	Findings
2012	Higa	Retention	N = 13 Qualitative Study	
2014	Koester	Retention	N = 31 Inmates LWH, 5 Patient Navigators Qualitative Study	Positive association with socially concordant patient navigators
2015	Metsch	Retention in oral health care	N = 600 PLWH Standard of Care Patient Navigation Incentives given for participation	Increased oral healthcare utilization for 12 months for patient navigation participants
2016	Giordano	Retention	N = 460 Newly Diagnosed or Out of Care PLWH Standard of Care Patient Navigation	No significant results
2016	Metsch	Viral Suppression	N = 800 PLWH and a substance abuse disorder Standard of Care Patient Navigation Incentivized Patient Navigation	No significant results
2018	Cook	Linkage	N = 27 Qualitative Study	Reduction in barriers to care for patient navigation participants

Year	First Author	Measures	Population	Findings
2018	Cunningham	Viral Suppression	N = 356 Inmates and Convict LWH	Positive association with patient navigation and viral suppression
2018	Myers	Retention, Linkage	N = 270 Inmates LWH with a substance abuse disorder	Increased linkage for patient navigation patients
2018	Stitzer	Viral Suppression, Engagement	N = 316 Standard of Care Patient Navigation Incentives given for participation	No significant results
2019	Fuller	Retention	N = 24 Inmates LWH Qualitative Study	Increased retention for patient navigation participants
2019	Parnell	Retention	N = 11 PLWH, 9 Patient Navigators Qualitative Study	Increased engagement and motivation correlated with emotional and social support

APPENDIX B

PEER NAVIGATOR JOB DESCRIPTION

In accordance with the Mission Statement of Roper Saint Francis Healthcare organization and Vision Statement of the Ryan White HIV Program, the Peer Navigator is responsible for assisting enrolled patients access to primary HIV medical care and eligible supportive services. The Peer Navigator's focus should be on engagement and retention in medical care, building trust and knowledge in patients, and providing psychosocial support services in a way that is distinct from case management.

A high school diploma is required; some college is preferred. Specific education or experience in public health, social work, or patient advocacy is preferred, especially in an HIV setting. Experience in a similar professional setting, preferably healthcare is strongly preferred to include experience in patient navigation/advocacy preferred, especially in an HIV setting.

Candidate should also have a basic knowledge of HIV, STD's and viral hepatitis issues and treatments available. Candidate should also be proficient in communicating clearly and effectively in a multidisciplinary setting; in computer usage, especially Word, Excel, Outlook, and client database program; and have knowledge of organizational policies and procedures, of common safety hazards and precautions to establish a safe work environment, including HIPAA. Skill in identifying problems and recommending solutions. Skill in preparing and maintaining records, including client notes. Skill in establishing and maintaining effective working relationship with patients, hospital, medical staff and public. Ability to react calmly and effectively in a variety of situations. Ability to interpret, adapt, and apply guidelines and procedures. Must agree to participate in approved continued educational opportunities including on, and off-site trainings.

B.1 CONTACTS

Constant interaction with internal and external customers to include (but not limited to) patients, physicians, hospital personnel, general public, business community, AIDS service organizations.

B.2 WORK DEMANDS/ENVIRONMENT

Frequent sitting. Frequently requires long periods of working at a computer. Intermittent walking, standing, stooping, bending. May require lifting or moving items up to 25 lbs. Frequent use of finger/hand dexterity. Constant talking or hearing. Corrected hearing and vision to normal range. No exposure to blood, body fluids or tissue. Possible exposure to infectious materials, communicable diseases and/or other conditions common to a healthcare environment. Normal office environment. Requires work under stressful conditions, deadlines, and/or irregular hours. Ability to read and comprehend. Travel may be required.

B.3 JOB DUTIES AND RESPONSIBILITIES

Responsibilities include: empower patients to be active in their own healthcare, making use of skills such as motivational interviewing, and advocating for the patients' needs; disseminate information on community resources, including services available via the Ryan White Wellness Center; provide limited supportive services, such as ADAP applications and re-enrollments to graduated patients of the Wellness Center; provide psychosocial support that is distinct from mental health counseling; attend ongoing training and educational opportunities provided by the Ryan White Wellness Center and other partners; provide outreach services to out of care patients, such as letter or phone calls; and facilitate monthly support groups.

APPENDIX C

QUANTITATIVE DATA VARIABLES OF THE PEER NAVIGATION PROGRAM DATABASE

Table C.1. PNP Database Quantitative Variables

Name	Label	Values	Measurement Level
Patient ID	Generated by CAREWare	N/A	Nominal
Age	Patient age	N/A	Interval
Age Range	Patient age range	18-24 25-29 30-39 40-49 50-59 60+	Nominal
Gender	Patient self-identified gender	Male Female Transgender	Nominal
PNP Accepted	Patient accepted PNP services	0 No 1 Yes	Nominal
Viral Load – Initial	Patient viral load at January 1, 2016	N/A	Interval
Viral Suppression – Initial	Patient viral load less than 200 copies of HIV per mL of blood	0 No 1 Yes	Nominal
Viral Load – Follow Up	Patient viral load at December 31, 2018	N/A	Interval

Name	Label	Values	Measurement Level
Viral Suppression – Follow Up	Patient viral load less than 200 copies of HIV per mL of blood	0 No 1 Yes	Nominal
Total Visits	# of appointments kept during test period	N/A	Interval
Retention	Patient kept at least 6 appointments that were at least 90 days apart over 3 years	0 No 1 Yes	Nominal
2016 Visits	# of appointments kept in 2016	N/A	Interval
2016 Engagement	Patient kept at least 2 appointments that were at least 90 days apart in 2016	0 No 1 Yes	Nominal
2017 Visits	# of appointments kept in 2017	N/A	Interval
2017 Engagement	Patient kept at least 2 appointments that were at least 90 days apart in 2017	0 No 1 Yes	Nominal
2018 Visits	# of appointments kept in 2018	N/A	Interval
2018 Engagement	Patient kept at least 2 appointments that were at least 90 days apart in 2018	0 No 1 Yes	Nominal
HIV Risk Factor	Self-reported primary transmission mode of HIV	1 Heterosexual 2 MSM 3 Not Specified	Nominal

APPENDIX D

PATIENT INTERVIEW GUIDE – PNP

[INTERVIEWER NOTE: Begin each interview with a welcome. Explain the general purpose of this discussion and why these participants were chosen. Introduce the tape recorder and ask for consent. Outline general ground rules and discussion guidelines (i.e. all thoughts are important, no right or wrong answers, informal conversation). Make sure to address confidentiality and anonymity. Assure participants that names will not be used in any analyses or reports.]

INTERVIEWER: Thank you for joining me today despite the Coronavirus crisis and restrictions we are under. I hope you and your family are well. Unfortunately, I do not work for the Ryan White Wellness Center so I can not help with resources. However, if you have any questions or do need help, please contact your case manager. They are still working really hard to make sure you have everything you need during this stressful time.

[Allow time for COVID-19 questions, if needed.]

INTERVIEWER: We are here to talk about your experience at the Ryan White Wellness Center and its peer navigation program. **You may want to make sure that you are in a private, quiet room** because I would like your honest opinions on various questions. There are no right or wrong answers, and everything we discuss will be confidential.

INTERVIEWER: I will take notes, but please feel free to be informal. With your permission, I'll also record our session. This helps to make sure that I do not lose information and I can focus more on you and our conversation.

Before we get started, did you have enough time to review the consent form? Do you have any questions?

[Allow verbal consent from individuals that agree to participate. Others should be thanked and interview cancelled.]

INTERVIEWER: Let's begin by introducing ourselves. Remember that this information will not be published but knowing each other's names will make conversations smoother. If you are uncomfortable using your real name, feel free to use an alias. I'll start.

[Introductions]

START RECORDING

1. Tell me about your experience living with HIV?
    a. PROBE: What about experiences with shame or stigma?
    b. PROBE: Tell me about your social support networks.
2. What do you need to live well with HIV?
3. What was most important to you when seeking HIV care?
4. What were you told about the PNP when you became a patient?
    a. PROMPT: What have you heard about it since then?
5. Why do you think some people decide to participate and others choose not to?
    a. PROMPT: Why did you enroll in the PNP?
6. Now enrolled, tell me what you like most and least about the program?

7. Has the PNP influenced your thoughts, attitudes or behaviors about HIV care? If so, how?
    a. PROBE: In what ways did the PNP help you to take care of your health?
8. How do you typically connect with your Peer Navigator (phone, in person, texts)?
    a. PROBE: How often?
9. Do others know that you participate in the program?
    a. PROBE: Are they supportive – peers, partners or parents?
10. Knowing what the program is designed to do, what would you suggest for programming?
    a. PROMPT: If you could make any changes to the PNP, what would it be?
11. What – if anything – makes/made it hard for you to participate?
12. The PNP is federally funded via the Ryan White Care Act. Information about the RW funding. Did you know and what do you think about that?
13. HIV rates increased and SE new epicenter. What do you think?
    a. PROMPT: What does that mean for the PNP or programs like it?
14. We are in an unprecedented time with the Coronavirus. How has the virus affected your participation in the PNP?

Thank you for talking to me today. You gave great feedback. Are there any final comments or suggestions?

Before we leave, please make sure that you return your questionnaire form. If you have any questions or suggestions after today, please feel free to contact our office using the phone number on your consent form. Thank you!

APPENDIX E

PATIENT INTERVIEW GUIDE – NON-PNP

[INTERVIEWER NOTE: Begin each interview with a welcome. Explain the general purpose of this discussion and why these participants were chosen. Introduce the tape recorder and ask for consent. Outline general ground rules and discussion guidelines (i.e. all thoughts are important, no right or wrong answers, informal conversation). Make sure to address confidentiality and anonymity. Assure participants that names will not be used in any analyses or reports.]

INTERVIEWER: Thank you for joining me today despite the Coronavirus crisis and restrictions we are under. I hope you and your family are well. Unfortunately, I do not work for the Ryan White Wellness Center so I can not help with resources. However, if you have any questions or do need help, please contact your case manager. They are still working really hard to make sure you have everything you need during this stressful time.

[Allow time for COVID-19 questions, if needed.]

INTERVIEWER: We are here to talk about your experience at the Ryan White Wellness Center and its peer navigation program. **You may want to make sure that you are in a private, quiet room** because I would like your honest opinions on various questions. There are no right or wrong answers, and everything we discuss will be confidential.

INTERVIEWER: I will take notes, but please feel free to be informal. With your permission, I'll also record our session. This helps to make sure that I do not lose information and I can focus more on you and our conversation.

Before we get started, did you have enough time to review the consent form? Do you have any questions?

[Allow verbal consent from individuals that agree to participate. Others should be thanked and interview cancelled.]

INTERVIEWER: Let's begin by introducing ourselves. Remember that this information will not be published but knowing each other's names will make conversations smoother. If you are uncomfortable using your real name, feel free to use an alias. I'll start.

[Introductions]

START RECORDING.

1. I have a patient questionnaire that I would like to complete with you. Could you give me the answers to some questions about you? *[Complete the patient questionnaire form.]*
2. Tell me about your experience living with HIV?
    a. PROBE: What about experiences with shame or stigma?
    b. PROBE: Tell me about your social support networks.
3. What do you need to live well with HIV?
4. What was most important to you when seeking HIV care?
5. What were you told about the PNP when you became a patient?
    a. PROMPT: What have you heard about it since then?

6. Why do you think some people decide to participate and others choose not to?
    a. PROMPT: Why did you choose not to enroll in the PNP?
7. Knowing what the program is designed to do, what would you suggest for programming?
    a. PROMPT: If you could make any changes to the PNP, what would it be?
8. What – if anything – makes/made it hard for you to participate?
9. How do you ensure that you remain engaged in care?
    a. PROBE: Are there people (social support) or things (environmental) that help?
10. The PNP is federally funded via the Ryan White Care Act. Information about the RW funding. Did you know and what do you think about that?
11. HIV rates increased and SE new epicenter. What do you think?
    a. PROMPT: What does that mean for the PNP or programs like it?
12. We are in an unprecedented time with the Coronavirus. How has the virus affected your participation in the PNP?

Thank you for talking to me today. You gave great feedback. Are there any final comments or suggestions?

Before we leave, please make sure that you return your questionnaire form. If you have any questions or suggestions after today, please feel free to contact our office using the phone number on your consent form. Thank you!

APPENDIX F

PATIENT INTERVIEW QUESTIONNAIRE – PNP AND NON-PNP

How old are you?	_____________ (year)
What is your gender?	☐ Male ☐ Female ☐ Transgender ☐ Prefer not to answer
What is your marital or relationship status?	☐ Single ☐ Married ☐ Divorced/Widowed ☐ Unknown ☐ Prefer not to answer
What is your insurance status?	☐ Medicare/Medicaid ☐ Private – Employer ☐ Private – Individual ☐ VA/Tricare ☐ Uninsured ☐ Unknown

When were you diagnosed with HIV?	___________ (year)	
Have you ever been diagnosed with AIDS?	☐	Yes
	☐	No
If yes, when?	____________ (year)	
When did you become a patient of the Ryan White Wellness Center?	____________ (year)	
Are you enrolled in the Peer Navigation Program?	☐	Yes
	☐	No
How often do you miss medical appointments?	☐	Always
	☐	Sometimes
	☐	Hardly Ever
	☐	Never