ABSTRACT

Title of Document: THE ROLE OF DENIAL AND PERCEIVED HIV STIGMA AS BARRIERS TO ENGAGING IN HIV MEDICAL CARE AMONG HIV POSITIVE AFRICAN AMERICANS IN THE WASHINGTON, DC AREA

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HIV is a potentially fatal and highly stigmatized disease such that diagnosis with the disease is often met with high anxiety. Many people who test positive for HIV may not receive sufficient linkage to HIV care or do not remain engaged in continuous HIV medical care once they have entered care. While a considerable amount of research exists on referral, access, personal characteristics, and mental illness barriers associated with engagement in HIV medical care, far less attention has been given to psychosocial factors, specifically denial and perceived HIV stigma as important barriers to engaging in HIV medical care.

The purpose of this study was to determine whether denial and/or perceived HIV stigma are associated with engagement in HIV medical care for African-American people living with HIV/AIDS (PLWHA). Data were collected as part of a peer-based community health worker program (CHW), based in Washington DC, designed to link PLWHA to HIV medical care and services. Logistic regression analyses were performed to determine whether the psychosocial variables were predictors of engagement in HIV medical care.

Results indicated that disclosure is a major issue for this population, as 46% of the participants had not disclosed their HIV status to others. Separate analyses were conducted for the total sample (n=262) and with the disclosed sample (n=120). Results in the total sample revealed that disclosure of HIV status was associated with engagement in HIV status. PLWHA who disclosed HIV status to others were 2.1 times more likely to engage in HIV medical care than persons who had not disclosed HIV status. In the disclosed sample, gender, educational level and employment status were also associated with engagement in HIV medical care. Women and persons with low educational level and unemployed were less likely to engage in HIV medical care. Denial and perceived HIV stigma were not found to be independent predictors of engagement in HIV medical care when other covariates were included in the model. Disclosure of HIV status, gender and educational level were predictors of engagement in HIV medical care for this population. These obstacles to care may be amenable to disclosure and gender-specific interventions; and, therefore, warrant better understanding to improve outreach interventions to PLWHA who are not engaged in HIV medical care.

THE ROLE OF DENIAL AND PERCEIVED HIV STIGMA AS BARRIERS TO ENGAGING IN HIV MEDICAL CARE AMONG HIV POSITIVE AFRICAN AMERICANS IN THE WASHINGTON, DC AREA

By

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Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, College Park, in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2015

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Acknowledgements

Oh give thanks unto the Lord, for He is good! For His mercy endures forever. Psalm 118:1
Jesus I would not be writing this if it weren't for your mercy!!

To my family I would like to thank you for all your love and support over the years. Mom your support and unconditional love is amazing! I could not have asked for a better mother. Auntie you are like my second mother, your prayers and encouragement helped me make it through. I am sure you are tickled that I actually finished this PhD degree considering I was the person at 5 years of age that told you I hate school and was not going!! Bill you were always calling me your genius since I was 4 years old. Uncle Ted and Aunt Cynthia thank you for praying for me and telling me how blessed I am.

To my sisters Monica and Anesia thank you for not nagging me about when I was going to graduate. To all my nieces and nephews (Jessica, Jazzmine, Lauren, Akira, Dewayne, Terren, Jaylen, Jaden, Justice, Jordyn, Jaycen and Michal) I missed a lot of milestones and parties. I have so much time to make up for …To the Geiger-Beatty Family for supporting me spiritually, emotionally and financially- Emma, Joey, Tracye Beatty and all my cousins. To Hazel and Bryanna thank you for coming to visit me and taking me out for delicious meals. My Baltimore/ NABCOR family, Nana and Uncle Herchel, Jacqueline Cade, Toye Jenkins, Tracey Newsome, Tajuanda Singletary and Rhema book store thank you for all your love and support.

To Dr. Boekeloo, my advisor and mentor thank you for never giving up on me and giving me a second chance. I know I tried your patience many times!!! I have learned so much from you over the years and I am forever grateful! I could not have finished this without all your guidance and support. To my committee members, Dr. Suzanne Randolph, thank you for introducing me to the project and always telling me “is just a process”. You made the process so much easier because of all your wisdom and encouragement. Dr. Linda Aldorry, thank you for your encouragement and for telling me when to I needed to move on and not get stuck on a particular chapter. Dr. Mia Smith-Bynum, thank you for your hallway mentoring and, Dr. Min Qi Wang, I definitely could not have finished without all your statistics classes and your encouragement.

Ammie Bonsu and Jennifer Williams Clarke, Dr. Myava Clark, and Pascha Lee you guys were my rock that helped carry me through one of the most difficult times in my life… Thank you!! Corliss Hill, one of my first friends as an undergraduate at University of Maryland, you have been with me through it all and your support has been amazing.

To my friends, Dr. Monica Lathan-Dye, Charisse Rhone, Kimberlee Daniels, Jeanette Gossett, Dionne Williams, Carla Ford, and Sabrina Trader thank you. Eve-Lyn Johnson, you did not have to rent a hall and perform an intervention☺. To PROMISE, Dr. Renetta Tull, and Dr. Wendy Carter-Veale thank you. Dr. CV your help through all the dissertation houses and weekly calls helped me to stay on track… Your advice to put on my cape and tights and get over my fears…To Dr. Michelle Beadle –Holder, my writing partner who for the last three years we spent many days and nights at Capitol Technology University. Thank you for all your calm down and let’s think this through talks. To my UPENN and JHU coworkers, Shelia Hartgrove, Rachel Coates Knowles and Penny Spencer, thank you for all your calls over the years to see about my progress and to encourage me to keep going…To all my fellow students from BCH, Dr. Sylvette La-Touche –Howard, Iris Allen, Dr. Kim Mitchell, Dr. Brian Gilchrist, Dr. Ina Ramos, Dr. Deliya Wesley and Tawanna Sawyer you support meant so much to me. To BCH faculty and staff, Dr. Sharon Desmond Beverly Monis and Tina Madison thank you for all your help over the years! To all Positive Pathways participants and Community Health workers, Abby Charles and Courtney Coffey thank you!!

**This project was supported by a grant from AIDS United. This material is based upon work supported by the Corporation for National and Community Service under Social Innovation Fund Grant No. 10SIHDC001. Opinions or points of view expressed in this document are those of the author and do not necessarily reflect the official position of, or a position that is endorsed by, the Corporation or the Social Innovation Fund.

Dedication

I dedicate this dissertation to Pearl and Gary Geiger you were there when it all started and I wish you could be here to see the culmination. Thank you for being always being there for me. I miss you…

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Chapter 1: Introduction

Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) continues to be a significant public health problem in the United States (U.S.), even as we enter the fourth decade of the epidemic. At the end of 2010 there were approximately 33 million people worldwide living with HIV/AIDS (UNAIDS, 2012). According to the Centers for Disease Control and Prevention (CDC), approximately 1.2 million persons are living with HIV in the United States (CDC, 2012).

The HIV/AIDS epidemic is not equally distributed in the U.S. Studies have shown that African Americans are disproportionately burdened by the epidemic (CDC, 2012; Hall et al., 2008; Kaiser Family Foundation, 2012; Prejean et al., 2011). African Americans make up 44% of persons infected with HIV/AIDS even though they comprise 12% of the United States population (CDC, 2013; Kaiser Family Foundation, 2012; Prejean et al., 2011). Prejean and colleagues' surveillance study showed that from 2006-2009, African Americans had the highest rate of new infections annually compared to all other races and they represented 64% of the new HIV infections in the United States.

In the District of Columbia (DC), the epidemic is also highest among African Americans. According to DC's HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA),African Americans in DC have an HIV prevalence rate of 3.9%, which is very close to World Health Organization's (WHO) definition of a concentrated epidemic (HAHSTA, 2012 WHO, 2013). Given the epidemic rate of HIV/AIDS globally, nationally, and locally and among African Americans in particular, it remains a high priority that people living with HIV/AIDS have access to both immediate and continuous HIV medical care.

Studies have shown that there are multiple benefits to engagement in HIV medical care.

Effective HIV treatment with Highly Active Antiretroviral Treatment (HAART) has significantly decreased deaths from HIV/AIDS. Fang et al.'s (2008) analysis showed that patients with newly diagnosed asymptomatic HIV infection on HAART could expect to survive on average 21 years after HIV diagnosis. Equally important are results by Rodger and colleagues (2013) who reported that PLWHA who are on HAART and have a normal CD4 count[1] could expect to have similar life expectancies to persons who are not infected with HIV. Recent developments proclaim that engagement in HIV medical care and treatment with HAART contributes to the overall health and well-being of PLWHA, and is crucial to the prevention of new HIV infections (Cheever, 2007; Cohen et al., 2011; Giordano et al., 2007). Yet, continuous engagement in HIV/AIDS medical care remains a major public health problem.

Barriers to continuous engagement in HIV medical care for PLWHA could stem from many factors. For example, Garland and colleagues (2011) reported that after HIV counseling and testing, lack of referral to appropriate HIV medical care is one barrier. In addition, limited access to care is also barrier (Garland et al., 2011). Turner et al. (2000) found that among persons diagnosed with HIV who did not have health insurance or a usual source of care they delayed entering medical care more than 3 months after diagnosis (Turner et al., 2000). Similarly, Rajabiun et al. (2007) found that limited capacity to navigate a fragmented HIV medical care system impacts engagement in medical care because some PLWHA cannot get an appointment with their doctors in a timely manner, which can cause gaps in care. Other studies attribute limited engagement in medical care to mental health issues such as depression, anxiety, and substance abuse (Whetten, Reif, Whetten & Murphy-McMillian, 2008) and psychosocial

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[1] Normal CD4 count can range from 500cells/mm^3 to 1000 cells/ mm^3 (http://aids.gov/hiv-aids-basics/just-diagnosed-

factors: social support, denial, and stigma (Konkle-Parker, Erlen & Dubbert, 2008; Ryan, Forehand, Solomon, & Miller, 2008). Among these psychosocial factors denial and stigma are found to be associated with poorer health outcomes (Konkle-Parker, Erlen & Dubbert, 2008).

Statement of the Problem

A considerable amount of research exists on barriers associated with HIV medical care and treatment such as structural factors (e.g. access to care), personal characteristics, risk behavior (e.g. risky sexual behaviors and intravenous drug use), and mental illness factors (e.g. depression)(Heckman et al., 1998; Konkle-Parker, Erlan & Dubbert, 2008; McCoy et al., 2009; Pollini et al., 2011;Samet et al., 1994,1998; Tobias et al. 2007). However, far less attention has been paid by researchers to psychosocial factors as barriers. Psychosocial factors are characterized as psychological and social factors that determine how a person manages their HIV disease, including their acceptance or denial of their status as a PLWHA and their perception of stigma associated with HIV and PLWHA. Many of the studies conducted by researchers examining the predictors of engagement in HIV medical care, including that on denial and HIV stigma have been retrospective (Mugavero et al., 2009), qualitative (Beer et al., 2009; Konkle-Parker et al., 2008/2011; Rajibium et al., 2009), based on medical record abstraction (Rumptz et al., 2007; Ulett et al., 2009) and/or used surveillance data (Reed et al., 2009; Torian et al., 2008).

Current research has shown that engagement in HIV care can increase adherence to HIV treatment as well as decrease community viral load, transmission rates, emergent resistant HIV strains, and health care costs (Gardner et al., 2011; Mugarvero et al., 2007). The recent qualitative "Not in Care", study conducted by the CDC with PLWHA not engaged in HIV medical care after diagnosis, found that the psychosocial barriers (denial and perceived HIV stigma) were an issue nationwide and were not being addressed when looking at the health care utilization of PLWHA (Beer, Fagan, Valverde, & Bertolli, 2009; Fagan et al., 2010).

A few quantitative studies have focused on stigma and engagement in HIV medical care. For example, in a cross-sectional study with 202 PLWHA in Los Angeles, one-third reported experiencing high levels of stigma and those persons experiencing high levels of stigma were five times more likely to report poor access to HIV medical care (Sayles, Wong, Kinsler, Martin & Cunningham, 2009). Vanable, Carey, Blair and Littlewood (2006) also reported that PLWHA who experienced HIV stigma were less likely to engage in medical care and have lower treatment adherence. The results of the studies above indicate that HIV stigma can be detrimental to engagement in HIV medical care and treatment for PLWHA.

Although several studies have focused on HIV stigma as a predictor of adherence to HIV treatment there have been very few on how denial is also associated with adherence to HIV treatment and delay engagement in HIV medical care with PLWHA. Singh and colleagues (1999) conducted one of the first studies with 123 PLWHA to examine how psychosocial factors affect adherence to HIV treatment. They found that denial was associated with lower medication adherence (Singh et al., 1999). While the studies above provide great insights into understanding the factors that impede engagement in HIV medical care, the separate study of stigma or denial fails to consider how both interact as synergistic barriers.

Recent qualitative research has shown that HIV stigma and denial are major psychosocial barriers that contribute to PLWHA delaying entering HIV medical care (Beer et al., 2009; Konkle–Parker et al., 2008). Denial and HIV stigma are a double threat to engagement in HIV medical care and consequently the health and quality of life for of PLWHA (Beer et al., 2009; Kinsler et al., 2007; Vosvick et al., 2003).

There are a number of Washington, DC residents that have been diagnosed with HIV/AIDS. Of these, in 2010, 11% were not immediately linked to HIV medical care and 42% were not in continuous HIV medical care. The reasons for the low percentage of persons engaged in continuous care may be due to any one or combination of factors. Specifically, this dissertation quantitatively examines in a prospective cohort of PLWHA the association of denial and perceived HIV stigma with engagement in HIV medical care, in conjunction with the receipt of peer community health outreach worker (CHW) support. In 2011, Positive Pathways (PP) a peer community health worker project began in Washington, DC. Positive Pathways uses CHWs to help PLWHA access needed HIV medical care and services. The current study began the following year and uses the infrastructure already in place by Positive Pathways, which uses CHWs for recruitment and data collection. The CHWs are embedded in the community, medical and managed care organizations used as recruitment sites for this research study. Their role within this study is to recruit participants and conduct the baseline and follow-up assessments. Beyond their roles as recruiters and data collectors for this study, the CHWs, whose other job roles include helping clients link to their healthcare, may serve as a bridge to HIV medical care for participants enrolled in the study, and this may limit the generalizability of the results to PLWHA without access to a CHW and engagement in HIV medical care.

Purpose of the Study

The purpose of this quantitative study is to examine the relationship between denial and perceived HIV stigma as barriers to engagement in HIV medical care, among African American persons diagnosed with HIV/AIDS in Washington DC. The study is guided by an adapted version of the Andersen Behavioral Model of Health Care Utilization (ABM). The Andersen Behavioral Model examines predisposing, enabling, and need factors in relation to health care use. The psychosocial factors, denial and perceived HIV stigma, are added to the predisposing construct of the Andersen Behavioral Model. Specifically the study is undertaken to examine whether the psychosocial factors, denial and perceived HIV stigma, are independent and/or synergistic barriers to engagement in HIV medical care, after controlling for other predisposing, enabling and need factors that PLWHA experience. The examination of denial and stigma together is important, as their independent and interactive influence is not thoroughly understood in relation to HIV medical care engagement. This study seeks to understand (1) rates of denial and perceived HIV stigma in African- American HIV positive persons in the Washington, DC area, (2) independent effects of denial and perceived HIV stigma on engagement in HIV medical care, and (3) the interactive relationship of denial and perceived HIV stigma on engagement in HIV medical care.

Significance of Study

This study contributes to public health research on HIV/AIDS medical care and policy. Identifying psychosocial barriers specifically stigma and denial may provide insight into points of intervention along the HIV continuum of care-specifically at the linkage and retention steps. The findings can have an impact on both local and federal policies on linkage and engagement/retention in HIV medical care.

At the District of Columbia local level, DC has two programs that they have used to support engagement in HIV medical care for PLWHA. First, the red carpet program, which allows any DC resident newly diagnosed with HIV or persons who are not in engaged in HIV medical care to receive an HIV medical appointment within 1-2 days of request free of charge. The second, the Recapture Blitz program, focuses on reengaging PLWHA who are not accessing HIV medical care. These programs seek to decrease barriers to accessing HIV medical care for

PLWHA. This study seeks to show that as part of these and other local initiatives, screening for denial and perceived HIV stigma at entry points into care can help shed light on barriers for PLWHA engaging in HIV medical care in the District. At the federal level, the National HIV/AIDS Strategy (NHAS) emphasizes the need to focus on increasing linkage, retention and access to HIV care for communities disproportionately affected by HIV/AIDS. This study may help to address this goal by examining barriers to care for African Americans who make up the greatest proportion of persons infected with HIV/AIDS. This study can also inform Health Resources and Services Administration (HRSA)'s Special Projects of National Significance (SPNS) about barriers to linkages and access to care for PLWHA. Increasing the understanding of barriers that keep people out of care will help public health researchers better develop best practices and interventions as well as lobby for funding to increase linkage and engagement in HIV medical care.

This study may also provide insight into the possible benefits of initiation of the Affordable Care Act (ACA) for PLWHA. Implementation of ACA includes the expansion of Medicaid coverage for PLWHA. In 2011, prior to the passage of ACA, Washington, DC expanded its Medicaid program for PLWHA, and now has one of the highest health insurance coverage rates in the DC Metropolitan area. As a result of Medicaid expansion, DC has experienced a reduction in expenditures associated with medical care and HIV medications for PLWHA (DC DOH- SCSN, 2011). The District of Columbia's Medicaid expansion program can possibly serve as a model for other states implementing the ACA. Since PLWHA now have greater access to health insurance and quality care to help them remain engaged in HIV medical care, lack of insurance as a barrier is decreased. This study may suggest that access to care does not always equate to engagement. The psychosocial factors of denial and perceived HIV stigma may help explain why PLWHA, most of whom have access to health insurance, are not in continuous HIV medical care.

This study examines the differences in engagement in HIV medical care with two subpopulations of people living with HIV/AIDS (newly diagnosed and out of care). Newly diagnosed is defined as a person diagnosed with HIV within the past three months of (Shahani, et al., 2012). Out of care persons are defined as persons living with HIV who do not have a medical visit in the last 6 months (HRSA, 2011).

For persons newly diagnosed with HIV, it is very important that they are linked and begin HIV medical care and treatment early in the course of the disease. If care is not initiated soon after diagnosis, researchers have reported that is harder for these persons to reach an undetectable HIV viral load, they are more likely to transmit the virus, experience worse health outcomes, and even death. These studies have reported that with consistent HIV medical care and proper treatment PLWHA can live to an almost normal life expectancy (Hogg et al., 2013; Rodger et al., 2013). Unfortunately, there is a lack of surveillance information about newly diagnosed persons and their process of linking and engaging in continuous HIV medical care (Mugavero, Norton, & Saag, 2011). This study can shed some light on this process.

On the other hand, out of care individuals who are aware of HIV status but never entered care or have dropped out of care are an important population to study also. In this sub-population at least 42% of persons are aware of their HIV status but are not engaged in regular HV medical care. It is important to examine barriers to care for newly diagnosed and out of care persons that are at different points along the HIV care continuum. In spite of the fact, that these two groups may be different in regard to length of HIV infection and have different familiarities with health care utilization, they can experience the same psychosocial factors when it comes to engaging in

HIV medical care. Screening for denial and HIV stigma may improve linkage and engagement in HIV medical care.

The significance of HIV medical care utilization among PLWHA was emphasized by two major events that have changed the nation's approach to HIV prevention and care. These events include the National HIV/AIDS Strategy for the U.S and the HIV Prevention Trial Network (HPTN) 052 study. In July 2010, The White House Office of National AIDS Policy (ONAP) released the first ever comprehensive National HIV/AIDS Strategy for the country. The NHAS was developed to ensure that new infections become rare and that PLWHA receive access to the best medical care (NHAS, 2010). The major goals of the NHAS are to:

(1) Decrease the number of new HIV infections,

(2) Increase linkage, engagement and access to care for PLWHA, and

(3) Reduce health disparities associated with HIV/AIDS.

The second was the release of findings from the HTPN 052 study. Prior to the landmark HTPN 052 study, HIV treatment for PLWHA with HAART had been shown to be effective in reducing their HIV viral load to achieve viral suppression and decrease morbidity and mortality associated with HIV (Anema, Wood, & Montaner, 2008; Palella et al., 1998). Subsequently, in recent years, in addition to stabilizing the health of PLWHA, HAART has also been seen as a way to reduce the transmission of HIV to others (Lima et al., 2008). In August 2011, the National Institutes of Health (NIH) released the results from the HPTN 052 study.[2] This study was conducted with serodiscordant couples, and has provided evidence that PLWHA who are engaged in HIV medical care, on HAART and have a suppressed HIV viral load, are less likely

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[2] HTPN 052, was conducted with serodiscordant couples and has provided evidence that PLWHA that are engaged in HIV medical care, on Highly Active Antiretroviral Therapy (HAART) and have a suppressed HIV viral load decreases the probability of the HIV positive partner transmitting the virus to their sexual partner is close to zero. (Cohen et al., 2011)

to transmit the HIV virus to others. In this study there was a 96% reduction in HIV incidence among participants. This study bolstered evidence that HIV treatment can be used as a method of prevention. PLWHA engaged in continuous HIV medical care and on HAART have a greater likelihood of becoming virally suppressed which can enhance their overall health and lessens ones chances of transmitting the virus to others (Cohen et al. 2011). Treatment as Prevention can also be used to address one of the NHAS goals of decreasing the number of new HIV infections in the U.S.

In addition to the NHAS' goal of decreasing the number of new HIV infections, another goal is to increase linkage and engagement in HIV medical care for PLWHA. The CDC and HRSA, two major HIV research and care coordinating governmental agencies, have also set goals to link and engage people who are diagnosed with HIV within 3 months of diagnosis. Findings from this study can add to the current literature on engagement in HIV medical care and psychosocial barriers of denial and perceived HIV stigma, by quantitatively examining these factors with PLWHA who are newly diagnosed or have had a gap in HIV medical care utilization.

Conceptual Framework

The conceptual model is an adapted of the Andersen Behavioral Model of Health care utilization (ABM; Andersen, 1995) and is used to guide the study. The Andersen Behavioral Model is a comprehensive model used to study medical care engagement. The model suggests that engagement is influenced by a combination of several factors: predisposing (e.g., demographics--age, gender, and race/ethnicity), enabling (personal resources--e.g. health insurance) and need (e.g. transportation, housing). The Andersen model was modified by adding to the predisposing factors (the psychosocial factors denial and perceived HIV stigma); to the need factor (client needs and barriers, barriers to care scale and the clinical factors-CD4 count and HIV viral load).

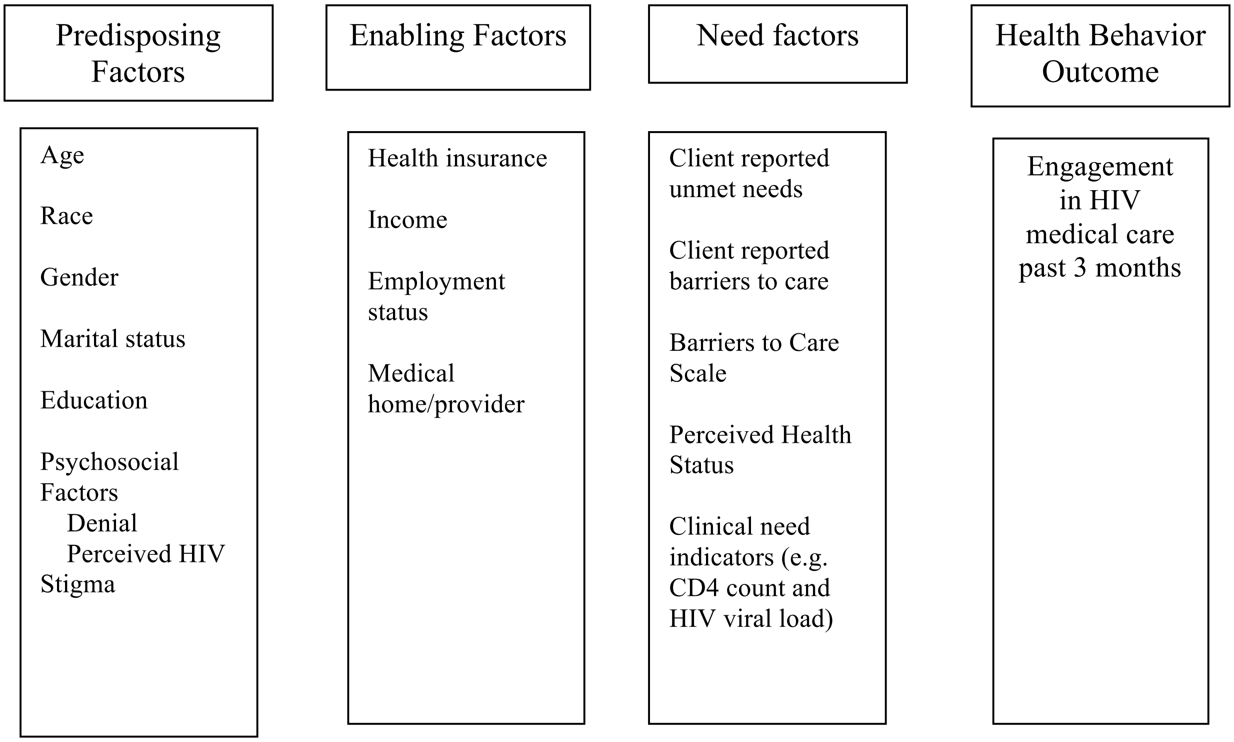

Figure 1-1 Conceptual Framework: Adjusted Andersen Behavioral Model

Research Questions and Hypotheses

Q1. What is the rate of denial among African-American PLWHA in and HIV resources-rich area?

Q2. What is the rate of perceived HIV stigma among African-American PLWHA in an HIV resource -rich area?

Q3. Do out of care PLWHA have higher rates of denial than newly diagnosed PLWHA?

H1: Out of care PLWHA will have higher rates of denial than newly diagnosed PLWHA.

Q4. Do out of care PLWHA have higher rates of perceived HIV stigma than newly diagnosed PLWHA?

H2: Out of care PLWHA will have higher rates of perceived HIV stigma than newly diagnosed PLWHA.

Q5. Does denial impact engagement in HIV medical care even after controlling for other potential predictors?

H3. Denial will be an independent predictor of engagement in HIV medical care.

H4. Denial will be a stronger independent predictor of engagement in HIV medical care than other factors.

Q6. Does perceived HIV stigma impact engagement in HIV medical care even after controlling for other potential predictors of engagement in HIV medical care?

H5. Perceived HIV stigma will be an independent predictor of HIV care engagement

Q7. Do denial and stigma interact in their prediction of engagement in HIV medical care?

  H6. Denial and stigma have a synergistic relationship when predicting engagement in HIV medical care.

Key Variables and Definition of Terms

Human Immunodeficiency Virus (HIV): HIV is the virus that causes AIDS. HIV attacks the immune system by destroying CD4 positive (CD4+) T cells, a type of white blood cell that is vital to fighting off infection. The destruction of these cells leaves people infected with HIV vulnerable to other infections, diseases and other complications. (National Institute of Allergy and Infectious Disease [NIAID], 2012) http://www.niaid.nih.gov/topics/HIVAIDS/Understanding/Pages/whatAreHIVAIDS.aspx

Acquired Immunodeficiency Virus (AIDS): AIDS is the final stage of HIV infection. A person infected with HIV is diagnosed with AIDS when he or she has one or more opportunistic infections, such as pneumonia or tuberculosis, and has a dangerously low number of CD4+ T cells (less than 200 cells per cubic millimeter of blood) (NIAID, 2012). http://www.niaid.nih.gov/topics/HIVAIDS/Understanding/Pages/whatAreHIVAIDS.aspx

Denial: The refusal to believe that the stressor (HIV) exists or "trying to push the reality of the situation away" or act as though the HIV is not real. The opposite of denial is a person who accepts the reality of the stressful situation and is engaged in the attempt to deal with the situation (Carver, Weintraub, & Sheier, 1989).

Perceived HIV Stigma: The personal experiences, fears of rejection, and perceived negative consequences of other people knowing that a person has HIV (Berger, Ferrans, & Lashley, 2001).

Chronic illness: Any disorder that persists over a long period and affects physical, emotional, intellectual, vocational, social or spiritual functioning. Chronic illness cannot be prevented by vaccine or cured by medication nor do they just disappear, but they can be managed (Taylor, 1999).

CD4 count: CD4 - T-cells (or T-lymphocytes) are white blood cells that play important roles in the immune system. There are two main types of T-cells. One type has molecules called CD4 on its surface; the "helper" cells organize the immune system's response to bacteria, fungi and viruses. http://www.AIDSmap.com/CD4-cell-counts/page/1044596/

HIV Viral load: HIV viral load is the term used to describe the amount of HIV in the blood. The more HIV in the blood, the faster a person's CD4 cells (immune system cells that fight infection) reduce, and the greater risk of them developing symptoms in the next few years. http://www.AIDSmap.com/Viral-load/page/1044622/

HIV viral suppression: An undetectable HIV viral load is defined as <50 copies/ml (Gardner et al. 2011).

HIV medical care: Engagement in HIV medical care: received first set of follow-up HIV medical care visits after HIV diagnosis. http://www.cdc.gov/hiv/pwp/linkage.html

Linkage to HIV medical care: Received initial HIV medical visit after HIV diagnosis or reengagement (CDC) at http://www.cdc.gov/hiv/pwp/linkage.html

Highly Active Antiretroviral Therapy: HAART is the name given to aggressive treatment regimens used to suppress HIV viral replication and the progression of HIV disease. The usual HAART regimen combines three or more different drugs such as two nucleoside reverse transcriptase inhibitors (NRTIs) and a protease inhibitor (PI), two NRTIs and a non-nucleoside reverse transcriptase inhibitor (NNRTI) or other such combinations. These HAART regimens have proven to reduce the amount of active virus and in some cases can lower the number of active virus until it is undetectable by current blood testing techniques. http://AIDS.about.com/od/hivAIDSletterh/g/haartdef.htm

Psychosocial Factors: Psychological and social factors that determine how a person copes or deals with a chronic disease /illness. (http://guidewhois.com/2011/04/what-is-psychosocial-factors/ Accessed February 19, 2013).

Community Health Worker: CHWs are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables CHWs to serve as a liaison, link, or intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. CHWs also build individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy (American Public Health Association [APHA], 2009).

Newly Diagnosed: a person with their first HIV seropositive diagnosis within the past 3 months (Shahani, 2012; Graham et al., 2013).

Out of care: A person diagnosed with HIV and failing to have a medical visit in the last 6 months of the measurement year (HRSA, 2011).

Continuous Engagement in HIV Medical care: a person diagnosed with HIV who completed at least 2 HIV medical visits in 12 months, at least 3 months apart (NHAS, 2010).

Chapter 2: Literature Review

Overview and Organization of Chapter

This chapter describes the literature on the HIV/AIDS epidemic nationally and in the District of Columbia. It presents a historical background and related statistics on HIV. Next, it highlights the importance of engagement in HIV treatment and medical care, the predictors of engagement, specifically the psychosocial predictors (perceived HIV stigma and denial). Finally, it describes the theoretical framework that guided this study, the Andersen Behavioral Model of Health Care Utilization.

HIV/AIDS Historical Background

Over 30 years ago, in June 1981, the United States was grappling with a disease in which five young previously healthy men were presenting to hospitals in New York and California with symptoms (e.g. Pneumocystis carinii, Pneumonia, Karposi Sarcoma, and Cytomegalovirus) causing them to be gravely ill. The treatment received by the men helped alleviate symptoms experienced by these patients but doctors did not know what was causing the symptoms or why these individuals were critically ill. At least two of the five patients died within 7 months of the incident cases (CDC, 1981; Kaplan et al., 1987).

Fast -forward almost four decades and it is now known that those five young men had AIDS and the cause was the HIV virus. Today, being diagnosed with HIV/AIDS in the United States is not an automatic death sentence. Studies have reported that HIV/AIDS is now a chronic illness that can be managed with antiretroviral treatment (Reynolds, 2011; Volberding & Deeks, 2010). These treatments are effective in decreasing opportunistic infections associated with HIV, HIV viral load, and morbidity and mortality for persons living with HIV/AIDS (Anema, Wood, & Montaner, 2008; Crum et al., 2006; Palella et al., 1998). Persons diagnosed with HIV are experiencing improvement in life expectancy with appropriate HIV medical care and treatment (Fang et al., 2007; Reynolds, 2011; Rodger et al., 2013; Sáez-Cirión et al., 2013). As life expectancy increases, it is important for PLWHA to have access to and remain engaged in continuous HIV medical care to ensure maximum benefits of antiretroviral therapy treatments. Despite effective antiretroviral treatments there are still approximately 33-54% of persons diagnosed with HIV/AIDS who are not engaging in regular HIV medical care (Fleming et al., 2002; Marks et al., 2010).

Snapshot of HIV Epidemic

It is estimated that approximately 1.2 million people are living with HIV in the United States, and each year there are approximately 40,000 new HIV infections (CDC, 2012). A recent study on the HIV/AIDS epidemic in the United States reported that from 2006-2009 the HIV incidence has remained stable. However*,* African Americans continue to see HIV incidence rates 7 times the rate of whites (Prejean et al., 2011).

African Americans and HIV/AIDS in the United States

African Americans are disproportionately affected by the HIV epidemic. African Americans make up 44% of persons infected with HIV/AIDS even though they comprise 12% of the United States population (CDC, 2013; Kaiser Family Foundation, 2012). The disparities seen in African Americans include higher numbers of HIV infections and AIDS diagnosis coupled with a greater number of blacks being diagnosed at advance stages in their illness. Studies measuring HIV incidence in the United States have recently been conducted and showcase the disparities. For example, one study examined HIV incidence using surveillance data from 16 states and cities, and found that blacks accounted for 42-46% of new infections, and carry the greatest burden of the HIV/AIDS epidemic (Prejean et al., 2011). Another study measured HIV incidence based on confirmed HIV antibody and serological tests from 39,000 newly infected persons, also reported that blacks made up 45 % of new HIV infections (Hall et al., 2008). In addition to having the highest incidence rates blacks also had the highest rates of new AIDS diagnosis. Specifically, African American men had a rate of 75[3], and African American women a rate of about 34 (CDC, 2012). Furthermore, HIV/AIDS incidence rates for other racial/ethnic groups have been decreasing or remained stable over time, but rates remain highest for blacks. Figure 2.1 shows that from 2008 to 2011, African Americans comprised the largest percentage of diagnoses of HIV infection each year (CDC, 2012).

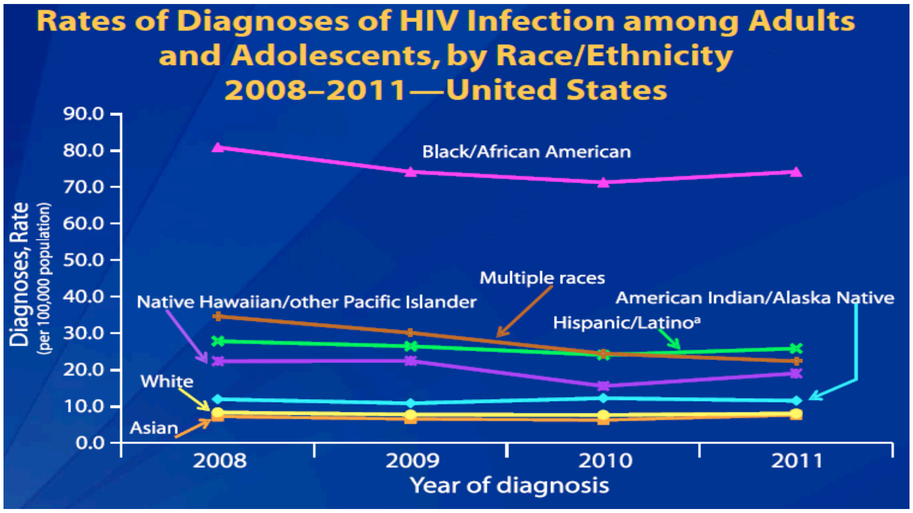

Figure 2-1 Rates of Diagnosis of HIV Infection among Adults and Adolescents by Race/Ethnicity, 2008-2011

Source: CDC, HIV Surveillance by Race/Ethnicity 2012

In addition to higher rates of HIV/AIDS among African Americans, it is reported that late diagnosis of HIV is also an issue. Approximately one-third of all blacks living with HIV have progressed to AIDS within one year after diagnosis. This can indicate that they have been living with the HIV for a long period of time before they were diagnosed or made the decision to seek treatment. Moreover, late diagnosis may also lead to higher mortality rates among African

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[3] The rate of HIV infections is per 100,000 among Black adults/adolescents. (CDC, 2012)

Americans. The mortality rate for African Americans living with HIV/AIDS 29.3/100,000 population is higher than all other race/ethnic groups (CDC, 2012).

Many studies report that the causes of high mortality among blacks occur because they are more likely to have never accessed HIV medical care, delayed entry into care after diagnosis, late initiation of HAART, entered care with advanced HIV infection, distrust medical providers and fear of stigma (Fagan et al., 2010; Rumptz et al., 2007; Tripath et al., 2011; Ulett et al., 2009; Whetten, 2008; Zaller et al., 2011). Taken together, these results continue to highlight the disparities in HIV infections in the United States for African Americans.

Washington, DC HIV/AIDS Epidemic

The District of Columbia, the site of the research study, has the highest HIV/AIDS diagnosis in the United States (CDC, 2009). Approximately 2.5% of the DC population is living with HIV. This exceeds the World Health Organization's definition of a generalized epidemic (1%); and ranks DC as top among all U.S. states and territories for U.S. AIDS cases (AIDS Lifecycle, 2012; HAHSTA, 2013). The disease also disproportionately burdens African Americans, as 75 % of the District's residents living with HIV are black (2.5% prevalence rate) (HAHSTA, 2013). Black women have a 2.4% prevalence rate and black males have a prevalence rate two times that of women at 5.7% (HAHSTA, 2013).

Washington DC Health Care Infrastructure

The District of Columbia has one of the largest HIV populations, and an abundance of HIV health care organizations, providers, and community- based organizations that provide HIV medical care and services. The DC Department of Health has made it a priority to increase HIV testing, linkage and retention in care efforts to make certain that PLWHA have access to continuous HIV medical care and treatment. One service that is provided, “treatment on demand,” is also known as the red carpet service. This service ensures any PLWHA newly diagnosed or who is not in engaged in HIV medical care can receive an HIV medical appointment within 1-2 days of request, free of charge. Red carpet service is provided at about 11 HIV organizations around the city (DC DOH- SCSN, 2011). This service reduces the barrier of access to HIV medical care in the District of Columbia.

As several studies report that a barrier to engagement in HIV medical care is the lack of health insurance (Bamford et al., 2007; Palacio et al., 1999; Turner et al., 2000). This is not the case in the District of Columbia. It is reported that over 90 % of DC residents have some form of health insurance, including persons that are 400 percent below poverty level (DC, DOH, 2011). Despite the abundance of HIV medical care and services in the District of Columbia and the majority of residents having health insurance, 42 % of PLWHA living in DC are not engaged in continuous HIV medical care and an even lower percentage are virally suppressed (HAHSTA, 2012).

Engagement in HIV Medical Care

Persons who receive a positive HIV test result should be linked to HIV medical care immediately after diagnosis. Entry into HIV medical care can provide the necessary treatment to help reduce the morbidity and mortality associated with the disease. Engagement in HIV medical care is a broad concept with different definitions. HRSA defines “engagement in care” as a spectrum of patient care, ranging from initial HIV diagnosis to full engagement HIV medical care. Figure 2.2 presents the engagement in HIV care continuum.

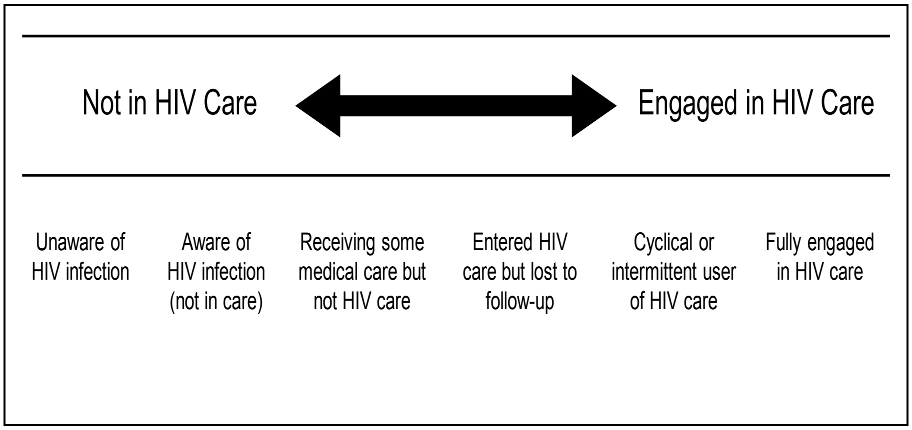


Figure 2-2 HRSA Engagement in HIV Care Continuum

Source: Cheever LW Clin Infect Dis 2007; 44:1500-2

The continuum spectrum ranges from persons unaware of their HIV infection to the other PLWHA fully engaged in HIV medical care. Engagement in HIV medical care encompasses all stages in the continuum such as linkage, retention, lost to follow-up and fully engaged in care (Cheever, 2007). One limitation of trying to measure engagement is that entry and exit into the continuum is often cyclic and overlap can occur in many of the stages (Gardner, 2012; Rajabiun et al., 2007). Persons may engage in medical care immediately following diagnosis, have a gap in care and then reengage after years of being out of care. Using the HIV care continuum, this study examined to what extent is denial and perceived HIV stigma pose barriers to PLWHA engaging in HIV medical care. Are denial and/ or HIV stigma the most important barrier(s), particularly at the initial stage in the continuum (newly diagnosed) or during reengagement in HIV medical care (out of care)? Are these two factors present singularly and/or in combination?

Engagement in HIV medical care is a national priority. The goal of engagement in medical HIV care and treatment is to get all PLWHA in continuous HIV medical care, on antiretroviral medication and to maintain viral suppression (HAHSTA, 2012; NHAS, 2010). The HIV treatment cascade developed by Gardner et al., (2011) and CDC (2011) appears in Figure 2.3. Within the cascade persons are tracked numerically over time from diagnosis to viral suppression in the United States. Nationally, about 79% of persons are aware of their HIV positive status; of those persons who are aware of their HIV status only about 40 % are engaged in regular HIV medical care; and of the 40 % engaged in regular HIV medical care about 75% are on antiretroviral medication; and, finally, of those persons on antiretroviral medication, approximately 19% are virally suppressed. This figure presents the grave details about the lack of engagement in HIV medical care in the United States. This study focused on perceived HIV stigma and denial and the extent to which these two factors are barriers to engagement in along the HIV care continuum.

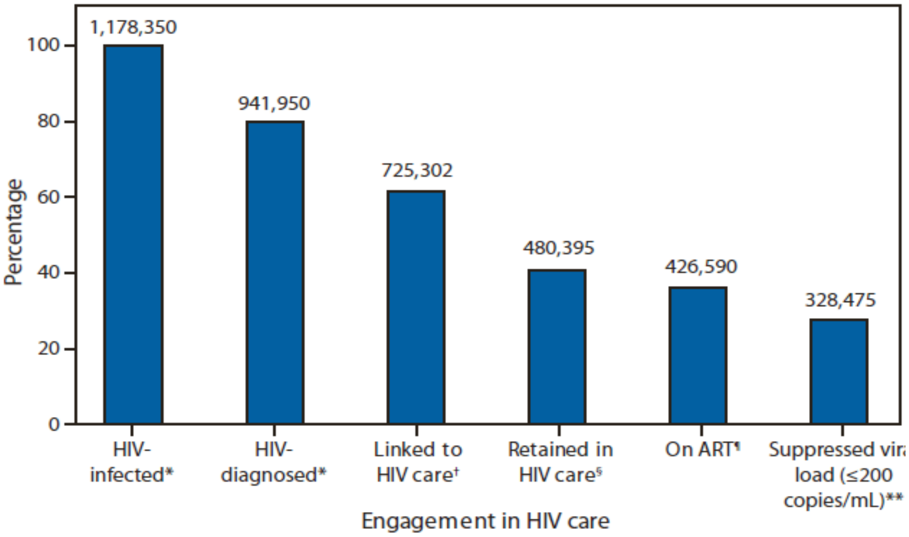


Figure 2-3 United States Engagement in HIV Care Cascade

Source: MMWR December 2, 2011 / 60(47); 1618-1623

Similar to the national cascade, the DC Engagement in HIV care cascade (Figure 2.4) reflects the national engagement in care numbers with about 44% of PLWHA not engaged in continuous HIV medical care.

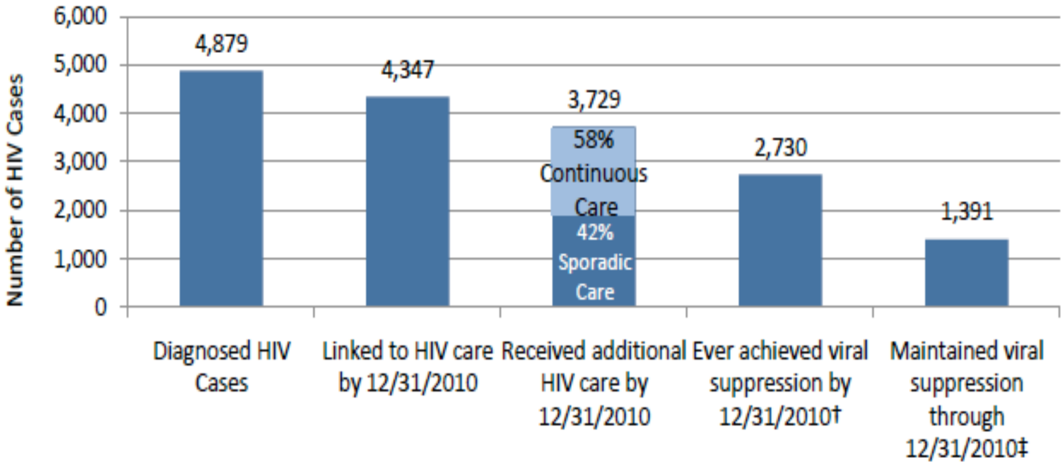


Figure 2-4 Washington DC Engagement in HIV Care Cascade

Source: DC DOH, HAHSTA 2011 Annual report

Studies on engagement in HIV medical care

Engagement in HIV care and treatment is a lifelong commitment and is important for the management of HIV/AIDS and prevention of new HIV infections. Since approximately 20 % of PLWHA have maintained HIV viral load suppression more needs to be done to ensure engagement in HIV medical care. Mugavero (2008) noted that there needs to be improvements in engagement in HIV medical care as PLWHA and the population at large will not be able to reap the benefits of advances in HIV treatment. The lack of research in this area recently led the editorial staff of the *Journal of Clinical Infectious Diseases,* in 2011 to devote an entire issue to engagement in HIV medical care.

The articles included in this journal focused on predictors of engagement in HIV care among particular subpopulations in the United States. For example, in their article on men who have sex with men (MSM) Christopoulos, Das, and Colfax (2011), suggested that engagement in care has not been thoroughly studied in this population; and found that predictors of engagement in care for MSM include race/ethnicity, sexual orientation and intravenous drug use. For women, the main barriers of engagement include: stigma, lack of transportation, being African

American, and poverty (Aziz & Smith, 2011); and for heterosexual men the major barriers were stigma, distrust, incarceration and drug abuse (Zaller, Fu Nunn & Beckwith, 2011). These studies all showed that African Americans are disproportionally affected by HIV/AIDS and have lower engagement in HIV medical care relative to other groups. This study focused specifically on African American PLWHA.

National initiatives to address engagement in HIV medical care

Engagement in HIV medical care has become a worldwide and national priority. The high rates of PLWHA who are not engaged in continuous HIV medical care in the United Stated has led federal agencies (e.g., CDC, HRSA, ONAP) to implement a variety of initiatives to increase HIV testing and engagement in HIV medical care. First, in 2006, CDC released an HIV testing recommendation that provided for routine HIV opt- out testing in medical care settings. This recommendation was necessary because it is estimated that 25 % of persons with HIV are not aware of their HIV status (CDC, 2006; Marks et al., 2006). In addition, the recommendation allows for routine screening in medical facilities, where patients can be tested for HIV unless they inform their doctor they do not want to be tested for HIV. Also, the recommendation has led to additional focus on HIV testing and immediate linkage to medical care after HIV diagnosis, both nationally and locally. Mugavero et al. (2009) suggest that because of this recommendation more PLWHA will be identified and need to be linked and engaged in HIV medical care.

In addition to recommendations on HIV testing, many federal agencies released recommendations to increase PLWHA’s engagement in HIV medical care. This is in response to the only 40% of PLWHA engaged in continuous HIV medical care after diagnosis in the United States (Gardner et al., 2005). In 2007, CDC released its HIV Strategic Prevention Plan, with the goal of linking 80% of persons diagnosed with HIV in medical care within 3 months. Soon after

CDC released their plan, the NHAS released its linkage goal but added a time frame that by 2015, 85% of people diagnosed with HIV in the U.S. will be linked to HIV medical care within 3 months of diagnosis. These recommendations are important because of their potential to provide evidence for the effectiveness of HIV treatment as prevention research and initiatives. They also demonstrate the need for additional research on barriers to PLWHA engaging in HIV medical care. Moreover, identifying barriers to engagement in care across the HIV care continuum is vital to get as many PLWHA from diagnosis to viral suppression maintenance. The shorter the time is from diagnosis to viral suppression, the bigger the public health impact that can be made on the HIV epidemic and on individual and population health.

Effective strategies and interventions have been investigated to determine the best way to engage PLWHA in HIV medical care as early as possible. One of the most widely used strategy that has proven to be effective at keeping PLWHA in medical care has been the use of case management services. The first randomized control trial testing the effectiveness of case management was the CDC-funded Antiretroviral Treatment Access Study (ARTAS) study. Gardner et al. (2005) developed ARTAS to determine if newly diagnosed persons with HIV referred to case managers vs. receiving information about HIV services and resources would increase linkage to medical care within 90 days of diagnosis. They found that persons who were referred to case management services were more likely to have a medical visit within 6 months of diagnosis as compared to those who only received information about HIV services and resources (Gardner et al., 2005).

Also, results from HRSA's Special Programs of National Significance (SPNS) results also showed that utilization of case management services increased engagement in HIV medical care (Draine et al., 2011). Case management services have proven to be effective in linking and retaining persons in HIV medical care. Despite research initiatives that are aimed at increasing engagement in care and research showing that case management is an effective engagement strategy, lack of engagement in HIV medical care persist for a large proportion of PLWHA. Thus, more research is needed to demonstrate the best ways to ensure that PLWHA are engaged in care (Gardner et al., 2011). Another strategy that has been suggested is the use of peer–based community health workers to link and engage people in HIV medical care (Bradford et al., 2007).

CHW Strategy to Promote engagement in HIV medical care

Community Health Worker Model

Community Health Workers have been called by various names over the years such as: peer navigators, lay health workers, community advisors and outreach worker (Hardy et al., 2005; Lewin et al., 2006; Wells et al., 2008). The American Public Health Association (APHA) has presented a broad definition of a Community health worker stating that, CHWs are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables CHWs to serve as a liaison, link, or intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. CHWs also build individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy.

One of a CHWs primary goal can be to provide individualized assistance to connect persons in need of health care to medical care. The assistance provided by the CHW can include: reminding clients of medical appointments, educating and answering clients questions about their disease, and helping to address barriers associated with engaging in medical care. CHWs have been shown to be effective in helping persons manage medical care for chronic diseases such as diabetes (Norris et al., 2006), cancer (Wells et al., 2008), and hypertension (Brownstein et al., 2007). With the success of CHWs in other chronic illnesses, their use has received increased focus as an effective strategy to linking and engaging PLWHA. A peer community health worker can be a person infected and /or affected by a particular disease, or a trusted member from the community.

A peer CHW can have the unique ability to connect with PLWHA, in addition to providing social support needed to navigate the sometimes-complex health care system. Social support has been shown to have a positive relationship with medical care access in PLWHA (Galvan et al., 2008). The use of CHWs has been increasing with People living with HIV/AIDS to help them adhere to their HIV antiretroviral medications. Furthermore, CHWs can be effective in helping PLWHA with reduction of barriers to engagement in HIV medical care.

Bradford et al. (2007) found that using HIV patient navigators and paraprofessionals in a 12-month longitudinal study to were effective in helping increase PLWHA's engagement and retention in HIV medical care. These researchers examined financial, structural and personal barriers to HIV medical care. They reported that all barriers to care were significantly reduced at 6-month and 12-month follow-ups; and, as a result, many patients had fewer missed medical appointments (Bradford et al., 2007). A more recent study of the Positive Choices program enrolled 449 PLWHA in Indiana to increase HIV medication adherence. Participants were randomly assigned to the treatment group (lay health worker + case management) and a control group (standard of care-case management only) and followed for one year. The Positive Choices treatment group within a year had greater HIV antiretroviral treatment adherence than the control group and were more likely to be virally suppressed. (Roth et al., 2012) These studies lend some evidence to the benefit of CHWs in helping reduce barriers associated with engagement in HIV medical care along the HIV continuum of care. In addition to viral suppression, they have been used to help increase retention in HIV medical care and medication adherence, a few researchers in sub-Saharan African countries have reported that CHWs have also been effective in reducing stigma associated with HIV treatment adherence (Apondi et al., 2007; Arem et al., 2011; Johnson & Khanna, 2004). The effectiveness of CHWs in decreasing denial and stigma in PLWHA has not been examined in the United States.

DC Initiatives for engagement in HIV medical care

In 2011, the Positive Pathways (PP) program began in DC as a strategy to help link and engage PLWHA in HIV medical care. PP uses the peer community CHW model to provide support to newly diagnosed and out of care PLWHA to become fully engaged in HIV medical care. Despite health insurance, HIV medical care, case management and CHW strategies in place there are still approximately 40 % of PLWHA not engaged in HIV medical care, as reported by Gardner's cascade and locally by the DC Department of Health. Moreover, the results suggest that there are additional barriers outside of the above-mentioned strategies that hinder engagement in HIV medical care. This study hypothesized that perceived HIV stigma and denial that are keeping PLWHA from engaging in HIV medical care. This study examined, with peer CHW support, the level of denial and perceived HIV stigma PLWHA experienced and whether participants stay engaged in HIV medical care along the HIV care continuum.

Benefits of engagement in HIV medical care

The Infectious Disease Society of America recommends that primary medical care for asymptomatic HIV patients occur at least once every six months and if patients are on antiretroviral treatment, every 3 months (Aberg et al., 2004). In addition, some researchers also suggest that the optimum interval for patients to receive primary medical care, depending on treatment regimens is about every 3 months (Napravnik et al., 2006; Rajabiun et al., 2007).

Early entry and engagement into HIV medical care and treatment has significant benefits. One such benefit is increased survival; Giordano et al. (2007) explored the relationship between poor retention in HIV care and survival rates in 2619 newly HIV diagnosed men who had received care at a Veterans Affairs hospital. Results showed that patients who had fewer medical visits had increased mortality (Giordano et al., 2007).

It is has also been shown that lack of engagement in HIV medical care is associated with worse individual outcomes. These can include severe immune system suppression and a quicker progression to AIDS diagnosis (Moore & Keruly, 2007). Engagement in medical care is essential if people living with HIV are going to benefit from life-prolonging HIV care and antiretroviral treatment (Rumptz et al., 2007). As engagement in care is beneficial, it is important to identify predictors of engagement in HIV medical care for PLWHA to determine where along the continuum of care interventions may be needed.

Predictors of engagement in HIV medical care

A significant amount of researchers have focused on identifying predisposing, enabling and need predictors of engagement in HIV medical care and treatment; Samet et al., (1994, 1998, 2001) identified gender, drug use, immigrant status, poor social support, age, and method of HIV result notification); Mugavero et al. 2009 found age, gender, minority group status, substance use, and lack of health insurance (Mugavero et al., 2009). Turner et al.(2000) identified African Americans, lack of trust/confidence in health care, insurance, and usual place of care as predictors; and Torian et al.(2008) found that diagnosis at a community center and/or city correctional system, race-nonwhite, born outside the US , and injection drug user (IDU) were significant predictors (Torian et al., 2008; Turner et al.,2000). Predictors can act as barriers or facilitators to PLWHA engaging in HIV medical care.

Many researchers have been reported on the predictors for delay in engagement in HIV medical by people living with HIV/AIDS. The predisposing factors of age (Bamford et al., 2010; Giordano et al., 2005;Mugavero et al., 2009; Pollini et al., 2011); gender (Aziz & Smith, 2011;Mugavero et al., 2009,); race (Giordano et al., 2005; Mugavero et al., 2009; Simard et al., 2012;Turner et al., 2000; Ulett et al., 2009); marital status (Samet et al., 1998) and educational level (Simard et al., 2012) all have been shown to be predictors of PLWHA engagement in HIV medical care.

Factors that that have been shown to enable PLWHA to get into care are health insurance (Mugavero et al., 2009, Pollini et al., 2011, Turner et al., 2000); income (Aziz & Smith, 2011); and having a medical home/usual place of medical care (Turner et al., 2000). PLWHA have reported to needing financial assistance, housing, benefits assistance, transportation, mental health care, food, and substance abuse treatment to help them receive medical care (Rumptz et al., 2007). Barriers to receiving care can include: transportation, homelessness, and lack of money or insurance (Beer et al., 2009; Heckman et al., 1998); and clinical need indicators such as CD4 count and HIV viral load (Ulett et al., 2009).

Predisposing psychosocial factors that have been mentioned as barriers to PLWHA attending medical care are denial (Beer et al., 2009; Konkle-Parker et al.2011; Singh et al., 1999); and perceived HIV stigma (Berger et al., 2001; Heckman et al., 1998; Zaller et al., 2011).

In the next section, the psychosocial factors will be explored further. Many of the studies that examine delay in engagement in care focus on individual level predictors and look at them retrospectively or qualitatively. Mayer indicated that many providers and other studies discount the importance of psychosocial barriers in assessing why PLWHA are not engaged in medical care (Mayer, 2011). This study will add to the literature by looking prospectively at the psychosocial factors denial and perceived HIV stigma as barriers to engagement.

Stigma

Construct Evolution

Goffman (1963) was one of the first social psychologists to write about stigma and in particular health-related stigma. He defined stigma as an attribute that is deeply discrediting, and the social identity of the sick person is labeled as "spoiled identity". He further explains how the stigma constitutes a relationship between the attribute and the stereotype attached to the person (Goffman, 1963). After Goffman's initial research on stigma other researchers attempted to conceptualize it from a broad to a more a focused concept. For example, Link, and Phelan (2001) set out to define stigma as the inter-relatedness of labeling, stereotyping, separation, status loss and discrimination. The successive conceptualizations of stigma allow for clearer understanding of the relationship between stigma, personal experiences and health related outcomes (Link, and Phelan, 2001).

Health related Stigma

Health-related stigma is defined as a "personal experience that can be characterized by exclusion, rejection, blame, or devaluation" (pg.2) which results from anticipation of discrimination because of diagnosis with a specific health condition (Caltado, Jahan & Pongquan, 2012; Scambler, 2009). Studies have examined ways in which stigma is associated with a number of chronic illnesses and health issues. These illnesses and health issues include:

mental illness (Babic, 2010;Boyd, 2003; Corrigan & Watson, 2004); disabilities (Tate et al., 1994), sexually transmitted diseases (STDs) (Fortenbery et al., 2002;Rusch et al. 2008); cancer (Lebel & Devins, 2008; Caltado, Jahan & Pongquan, 2012); substance use disorders (Rao et al. 2009); and HIV/AIDS (Galvan et al., 2008; Sayles et al., 2009). For example, a national study conducted with 192 persons diagnosed with lung cancer, found that lung cancer stigma was associated with greater depression and lower quality of life (Caltado, Jahan & Pongquan, 2012).

Earnshaw and Quinn (2012) conducted a cross-sectional study examining the influence of stigma from workers in health care settings on the quality of life for persons diagnosed with chronic illnesses. They studied 184 college students living with chronic illnesses in Connecticut. Participants were asked to complete an online survey that measured internalized, experienced and anticipated stigma on quality of life. Findings showed that persons, who internalized, experienced and anticipated stigma from health care workers accessed health care less and had lower quality of life. This study is important to show how stigma affects persons with chronic diseases. A limitation of this study is that the sample did not include any PLWHA (Earnshaw and Quinn, 2012).

Health-related stigma associated with chronic illnesses can have a negative impact on a person's quality of life and their decisions to access medical care needed to treat their illness. Fear of stigma can create increased psychological and psychiatric problems, non- disclosure of illness to others, and delays in seeking medical care and treatment (Van Brakel, 2006). These issues can also be seen in persons diagnosed with HIV/AIDS.

HIV/AIDS Related Stigma

HIV/AIDS is a highly stigmatizing health condition because it is a potentially fatal disease and a communicable disease. There is also a lack of population knowledge about HIV and how it is transmitted (Kaiser Family Foundation, 2011); and HIV/AIDS is associated with marginalized populations such as sexual minorities, racial/ethnic minorities, and intravenous drug users (Bunn et al., 2007; Herek, 2002; Parker & Aggleton, 2003). HIV/AIDS stigma experienced by marginalized populations can cause PLWHA to identify with the "spoiled identity" term described by Goffman (Goffman, 1963; Parker& Aggelton, 2003). Herek (1999) defines HIV/AIDS stigma as a result of" prejudice, bias and discrimination directed at PLWHA."

Marginalized populations are greatly affected by HIV/AIDS. Several researchers have examined the effects of stigma on marginalized populations who carry the greatest burden of the HIV/AIDS epidemics (Darrow, Montanea, & Gladwin, 2009; Galvan et al., 2008; Radcliffe et al., 2010). For instance, Swendeman et al. (2006) conducted a study with 147 young people living with HIV/AIDS in California and New York. They found that gay and bisexual youth had experienced more HIV stigma than heterosexual youth and more than half of the youth experienced stigma since their diagnosis (Swendeman et al., 2006). Also, in a study by Galvan et al. (2008) conducted with HIV positive African Americans in Los Angeles, California they examined predictors of HIV stigma in this population. They suggested that HIV stigma is greatest for African Americans since they bear the greatest burden of the HIV disease (Galvan et al., 2008). In contrast, Rao et al. (2008) examined cross-cultural differences of PLWHA, and they reported no difference in felt stigma between African Americans and Whites but that the two groups did perceive and experienced stigma differently. Blacks experienced more discrimination than other groups and Whites expressed the need to keep their HIV status a secret for fear of experiencing prejudice or discrimination (Rao et al., 2008). HIV/AIDS Stigma can negatively affect PLWHA, and subsequently how they experience stigma could have an effect on their engagement in HIV medical care.

Types of HIV Stigma

A review of the literature reveals PLWHA can experience various forms of stigma after diagnosis with HIV stigma both socially and individually. Within the stigma literature, HIV/AIDS stigma can be conceptualized in three main ways: enacted, internalized, and perceived HIV stigma. First, enacted stigma occurs from interactions with others where the PLWHA may experience discrimination, prejudice and stereotyping (Bunn et al, 2007; Galvan, et al., 2008; Van Brakel, 2006; Varni et al., 2012). For instance, Varni and colleagues (2012) measured the psychological consequences of enacted and felt stigma on outcomes with PLWHA. Increased enacted stigma was suggested to increase anxiety for PLWHA (Varni et.al, 2012). Second, internalized stigma comes about when people internalize negative beliefs and stereotypes associated with a diagnosis of HIV (Link, 1987; Sayles et al., 2009). PLWHA experience internalized stigma as feelings of shame, guilt and non-disclosure of HIV status (Kalichman et al., 2009). Third, perceived stigma is the PLWHA's belief, fear, and anticipation that disclosure of HIV status will lead to discrimination (Berger et al., 2001; Galvan et al., 2008; Varni et al., 2012).

Perceived HIV stigma is associated with increased depression, decreased disclosure and access to health care. One study by Sowell et al. (1997) in rural Georgia examined the extent that perceived HIV stigma, needed resources and disclosure were present in the sample of HIV positive women receiving HIV medical care and services from health care and community based organizations. They recruited about 82 women and conducted interviews with them on questions about demographics, HIV resources available, and perceptions of stigma and disclosure patterns. Results showed that approximately 40 % of women reported the presence of perceived stigma and fear of discrimination by others. The perception of how people (e.g. family, friends and health care providers) view them can be the debilitating and hinder their engagement in HIV medical care (Sowell et al., 1997). Perceived HIV stigma has been indicated as an important and major barrier to HIV testing, and also for PLWHA disclosing status to others and entering medical care (Derlega et al., 2002).

HIV Stigma and Health Care Environment

In the United States and Washington, DC a number of PLWHA are not taking advantage of HIV medical care and antiretroviral treatment necessary to decrease morbidity and mortality associated with HIV disease. Understanding how HIV/AIDS stigma affects gaps in HIV medical care and treatment is important to lessen negative health outcomes for persons diagnosed with HIV.

Research has shown that PLWHA who encounter or perceive HIV/AIDS stigma from health care professionals are less likely to engage in HIV medical care (Kinsler et al., 2007; Sayles et al., 2007, 2009). Engaging in HIV medical care helps keep the HIV infection under control and can enhance the health and quality of quality of life for PLWHA. Some researchers have examined attitudes and perceptions of health care professionals in providing care to PLWHA (Ding et al., 2005; Reis et al., 2005). A cross-sectional study in the US examining physician's attitudes towards their HIV positive IDU patients found that about 23% percent of the physicians had negative attitudes toward their patients. It is suggested that the negative attitudes of physicians toward IDU patients contributed to lower percentage of patients receiving HIV antiretroviral medications (Ding et al., 2005).

At the same time, PLWHA also have negative views of health care professionals and medical care environments, as they may have experienced and/or perceive stigma from medical providers. Perceived stigma by PLWHA from within the medical care settings may discourage patients from accessing needed health care services. Schuster et al. (2005) using the HIV Cost and Services Utilization Study (HCSUS), a national dataset, found that approximately 26% of PLWHA perceive they have experienced discrimination from their health care providers (Schuster et al., 2005). In another study, researchers from California conducted a study with low income PLWHA to assess the relationship between perceived stigma from a health care provider and access to medical care (Kinsler et al., 2007). Results indicated that between 20- 25 % of the sample had perceived stigma from a health care provider, and this was found to be associated with low access to medical care. Thus, PLWHA may delay entry to medical care, or have gaps in medical care because they have experienced or fear discrimination from health care professionals (Earnshaw & Quinn, 2012; Kinsler et al., 2007).

HIV Stigma and HIV Treatment Adherence

HAART has changed HIV from a fatal to a chronic illness. Adherence to HAART is very important for PLWHA to achieve HIV viral load suppression, reduce morbidity and mortality associated with HIV, and HIV transmission to others (Cohen et al., 2011). In addition, lack of adherence can lead to poorer health outcomes and possibly HIV viral resistance (Bangsberg, Moss & Deeks, 2004), and can present major challenges for PLWHA and providers (Beach, Keruly, & Moore, 2006).

HIV/AIDS related stigma also plays a role in PLWHA not consistently adhering to their antiretroviral treatment regimens. Indeed, prior research demonstrates that HIV/AIDS stigma is related to lower HIV treatment adherence in PLWHA (Chesney & Smith, 1999; Konkle-Parker et al., 2008; Rao et al., 2007; Rintamaki et al., 2006; Sayles et al., 2009; Vanable et al., 2006).

Sayles et al. (2009) conducted a cross-sectional study in California with 202 PLWHA. Participants were recruited from clinical and community-based organizations. They completed an anonymous survey to examine the association between internalized HIV stigma and self-reported access to care, regular source of HIV care, and antiretroviral therapy adherence; and to test whether mental health mediates these associations. Findings showed, one-third of participants reported high levels of stigma; 77% reported poor access to care; 42.5% reported suboptimal ART adherence. The results also indicated that high internalized HIV stigma was associated with lower reported treatment adherence and access to care (Sayles et al., 2009).

Rao and colleagues (2007) conducted a qualitative study with 25 young people living with HIV (YPLWH) to determine barriers to medication adherence among this population. Respondents were asked to share experiences with HIV medication (e.g. side effects, skipping doses, and how to overcome barriers to non-adherence). Findings revealed that almost 50 % of youth skipped doses for fear of family and friends finding out about their HIV status. These studies are important to confirm that HIV stigma is associated with non-adherence to HIV medication (Rao et al., 2007).

HIV/AIDS stigma is a predictor of non-adherence to HIV medications not only in the United States but internationally as well. A number of studies conducted in the United States and internationally have reported HIV stigma as a predictor of lack of antiretroviral treatment adherence and engagement in HIV medical care (Bogart et al., 2010; Sayles et al., 2009; Skinner & Mfecane, 2004; Sumari-de Boer et al., 2012; Wolitski et al., 2009). Only consistent use of HAART will help PLWHA attain and maintain HIV viral suppression. In addition to HIV stigma's effects on treatment adherence it also is a root cause of lack of continuous engagement in HIV medical care.

HIV Stigma and Engagement in HIV Medical Care

Engagement in HIV medical care is important to ensure that PLWHA receive life-preserving medications that can increase survival and decrease HIV transmission to others

(Mayer, 2011; Mugavero, 2008; Samet et al., 2001). For this study, HIV medical care was operationalized as PLWHA attending HIV medical appointments with a physician who can prescribe HIV medications. HIV stigma has been identified as one of the most significant barriers to PLWHA seeking HIV medical care (Chesney & Smith, 1999; Herek et al. 2003; & Kalichman & Simbaya, 2003). Many studies have examined retrospectively the effects of HIV stigma on PLWHA delaying entry into HIV medical care (Beer et al., 2009; Konkle-Parker et al., 2011; Rajabiun et al., 2007). However, there are a few studies that prospectively examine HIV/AIDS stigma as a barrier for PLWHA entering and remaining engaged in HIV medical care.

Reece (2003), in a cross-sectional study with 132 HIV-positive persons examined the association between HIV stigma and remaining in medical care. Participants were asked to complete surveys that assessed physical and mental health status, health beliefs and HIV stigma. The outcome was appointments kept, and the study examined participants who returned for their follow-up appointment versus those who did not return. Results from this study showed that persons with higher levels of HIV-related stigma were less likely to return for medical care as compared to those persons with lower levels of HIV stigma (Reece, 2003). Similar findings were reported by Vanable and colleagues (2006) who found in their study of 221 PLWHA in New York, that HIV stigma was associated with a greater number of missed appointments and HIV-related symptoms (Vanable et al., 2006).

Furthermore, researchers from California using the HCSUS national dataset examined the association between HIV stigma and utilization of medical care and treatment adherence (Sayles, 2009). Results indicated that persons who reported higher levels of stigma were four times as likely to report lower medical care utilization. In addition to PLWHA, HIV providers also consider HIV stigma as a barrier to PLWHA utilizing HIV medical care. Reif, Golin and Smith

(2005) explored barriers to HIV medical care for PLWHA in the rural South. They surveyed 111 HIV/AIDS case managers and over half reported that HIV stigma is a major barrier to engagement in medical care for PLWHA attending their urban clinic (Reif, Golin and Smith 2005). The stigmatization associated with HIV/AIDS has been referred to as a second epidemic because of the considerable impact it has on the lives of PLWHA (Chesney & Smith, 1999). After diagnosis many persons because of the stigma associated with the disease may never perceive themselves in the same way and are concerned about how they will be treated by others (Carr & Gramling, 2004).

In sum, HIV stigma has an impact on the health care environment, HIV treatment adherence and HIV medical care engagement, which can impact health outcomes for PLWHA. In addition to HIV stigma being a barrier to HIV care some have suggested that denial of HIV status in PLWHA is also another psychosocial factor that keeps people from engaging in HIV medical care (Beer et al., 2009).

Measurement of HIV Stigma

Perceived HIV stigma was the type of HIV stigma examined in this study. The two HIV stigma measures that were considered to measure perceived HIV stigma in this study were the Sowell perceived HIV stigma scale (Sowell et al., 1997) and the Berger's HIV stigma scale – personalized stigma subscale (Berger, Ferrans & Lashley, 2001). The Sowell perceived HIV stigma scale is a 13-item scale developed by Sowell and colleagues to assess perceived HIV stigma in PLWHA. The scale is measured on a 4-point Likert scale from "not at all to often", and measures the feelings of fear, blame or shame related to HIV stigma status. In addition it examines the fear of losing friends and family because of HIV positive status. This scale was originally tested with HIV positive women in the rural South

The second scale considered was the Berger's HIV stigma scale. The Berger HIV stigma scale consists of 4 subscales - the personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes about people with HIV. The scale is measured on a 4-point Likert scale from "strongly disagree to strongly agree". The perceived stigma subscale scale measures the perception of the consequences from others knowing a PLWHA's HIV status. The Berger's HIV stigma and Sowell HIV stigma scales were shown to be reliable measures.

The personalized stigma subscale of Berger HIV stigma scale was used to measure perceived HIV stigma in this study and will be referred to as perceived HIV stigma scale throughout the rest of the document. The Berger's HIV stigma scale was chosen over the Sowell scale because it has been referred to as the standard HIV stigma scale and has been used in psychosocial studies with PLWHA (Rao et al., 2007; Varni et al., 2012). In addition, the scale has been used with African Americans, and PLWHA in urban and rural areas (Bunn et al., 2007; Galvan et al., 2008; Reif et al., 2005).

Denial

Construct Evolution

Denial is a multifaceted concept that has its origins in the psychology discipline. Sigmund Freud first proposed denial to be an unconscious process that "disavows reality" of an event taking place (Freud, 1924, cited in Livneh, 2009). Since Freud first coined denial it has been defined in a variety of ways. First, denial has been examined as a form of coping and/or defense mechanisms originating from internal factors such as anxiety, shame or fears (Dorpat, 1983; Wheeler and Lord, 1999). Second, denial has been hypothesized to stem from external factors (e.g. life threatening illness or event) (Breznitz, 1983; Carver et al., 1989; Goldberger, 1983; Horowitz, 1983; & Lazarus, 1983). Breznitz (1983) postulated that denial refers to efforts to protect oneself from external factors rather than internal life factors. Third, denial can originate from a combination of both internal and external factors (Lazarus, 1984; Wool and Goldberg 1987). Wool & Goldberg (1987) have argued that denial is an "unconscious disavowal of an external or internal threat". Fourth, denial has been conceptualized as types or models that may occur on a continuum or in stages (e.g. mild to severe) (Breznitz, 1983; Hackett and Caseem, 1974; Levine et al., 1994; Wool and Goldberg, 1987). Finally, denial has been hypothesized as denial like tendencies (Lazarus, 1983). Lazarus suggests that denial is not all or nothing and is determined by time and situations. In addition, he proposes that a person can experience partial or minimal denial to cope with a life threatening/stressful event such as diagnosis with a chronic illness (Lazarus & Folkman, 1983, 1984).

Individuals with chronic illnesses may go through processes before accepting their diagnosis. Having a chronic illness may change a person's sense of self and possibly there interaction with other people. As a result they can develop a "head in the sand" coping strategy of not wanting to deal with the diagnosis. A person may also try to forget the reality of the situation especially when there are no symptoms present. In short, denial can be viewed as a protective strategy used to buffer the individual from the impact of anxiety and perceived threat associated with a chronic illness diagnosis (Livneh, 2009).

Health Related Denial

Since Freud's first discussion of denial it has since been examined in medical and public health research as factors that impede a person's recognition of diagnosis with a chronic illness and their subsequent engagement in medical care. Denial often describes a person's response to diagnosis with a chronic illness (Telford, Kralik & Koch, 2006). Denial has been studied extensively in persons diagnosed with chronic illnesses and medical conditions such as cancer (Greer et al., 1989; Wool, 1986; Wool and Goldberg, 1987), heart disease (Hackett & Cassem, 1974; Havik & Maeland, 1986; Jacobsen & Lowery, 1992; & Levine et al., 1987), and mental illness (Saks, 2009).

However, the role of denial in chronic illnesses has been investigated with mixed results in regard to its effect on medical treatment delay, survival and health outcomes. For instance in patients diagnosed with cancer, Wool (1986) examined 20 women with breast cancer for denial of illness, and found that persons who were classified as deniers had an average of 20 months longer delay in seeking medical treatment than those who were not classified as deniers (Wool, 1986). However in contrast, Watson and colleagues (1984) studied 24 women newly diagnosed with breast cancer to determine how patients coped with cancer diagnosis; did they use denial or accept their diagnosis. The results revealed that the majority of women used denial to cope with their diagnosis, but they found no relationship between denial and delay in seeking medical care (Watson et al., 1984). Moreover, Chakravorty et al. (1993) supported this conclusion; they examined 75 patients with cancer for reasons they delayed presentation to care after diagnosis. They reported that the approximately 90% of patients used denial to cope with diagnosis. In addition more than half delayed entering medical care within three months after diagnosis, but there was no difference in the degree of denial exhibited by patients who delayed medical care for 3 months versus those who did not delay medical care (Chakravorty et al., 1993). These studies confirm the diverse interpretations on how denial affects engagement in medical care after diagnosis with a chronic illness.

Research has suggested that denial can be “beneficial and detrimental” to a patient’s health (Lazarus, 1983), as it can help to alleviate initial anxiety associated with chronic illness (Esteve et al., 1992; Folks, 1988; Julkunen & Saarinen, 1994), but can also keep individuals from engaging in vital medical care needed to treat the chronic illness (Beer et al., 2009; Levine et al., 1987). Consequently, as HIV is now classified as a chronic illness, denial has also been associated with HIV diagnosis. Denial of HIV diagnosis has been examined with outcomes such a quality of life (Gielen et al., 2001; Kamen et al., 2012; Vosvick et al., 2003) and HIV medication adherence (Weaver et al., 2005). However the role of denial with PLWHA as it relates to engagement in HIV medical care has not been widely examined.

Denial and HIV/AIDS

The receipt of an HIV diagnosis can be met with high anxiety. The emotional response to the diagnosis of a potentially fatal and chronic illness, such HIV can lead a person into denial. Denial of HIV in particular is denying the reality and significance of their HIV diagnosis says Raveis, Sigel and Corey (1998). In addition, Nam et al. (2008) says denial is when "a person has not fully adapted to their HIV status or had not accepted one's self". Denial can be a coping mechanism people use to deal with the shock of acquiring a stigmatized illness and social status (Nam et al., 2008). Among a sample of African-American HIV positive women, Watkins-Haynes et al. (2012) conducted in-depth interviews, to examine the effects of HIV on these women and how their perceptions of their HIV diagnosis changed over time. Participants were recruited from HIV medical and social services agencies in Chicago, IL. Some women reported being in denial after receiving diagnosis, and as a result not disclosing their HIV status to others for more than two years. (Watkins-Haynes et al., 2012)

Also as a result of being in denial many PLWHA delay entry or do not remain engaged in HIV medical care (Konkle–Parker et al., 2011). Psychosocial factors both positive and negative have been examined with HIV. Many researchers have explored the relationship between psychosocial factors and HIV disease progression (Antoni et al., 1995; Cole, 2008; Gore-Felton & Koopman, 2008; Ironside & Hayward, 2008). The use of negative psychosocial factor such as denial by HIV positive persons has been associated with lower immune functioning. In a study with newly diagnosed HIV positive gay men, Antoni and colleagues (1995) found that those men who used denial as a form of coping the year following notification of positive HIV status had significantly lower immune function. These results point to the fact that PLWHA who use denial to cope with disease can potentially speed up the HIV disease progression in their bodies that may lead to worse health outcomes (Antoni et al., 1995).

On the other hand, Ironside and Hayward (2008) reported that that positive psychosocial factors such as social support, positive coping and spirituality lead to better health outcomes for PLWHA (Ironside and Hayward, 2008). More research on negative psychosocial factors such as denial and its effect on HIV disease progression and engagement in HIV medical care is needed. Identifying denial in PLWHA is important in order to pinpoint which persons are at risk for non-adherence to HIV medication or dropping out of HIV medical care (Singh 1999). With the diagnosis of HIV a person can be asymptomatic for a number of years. This could possibly lead to a PLWHA using denial to cope with illness and be in denial for a number of years. The study focused on denial as a coping mechanism, in PLWHA and their refusal to believe that HIV exist or trying to act as though HIV is not real in their life.

Denial and HIV Medication Treatment Adherence

HIV medical care is important for PLWHA to receive the necessary HIV treatment, and disease progression monitoring to remain healthy. However, to take advantage of the benefits, PLWHA must remain adherent to HIV medications and remain engaged in HIV medical care (Nam et al., 2008). Denial has been reported to be a barrier to both HIV treatment adherence and engagement in HIV medical care. Undoubtedly there has been ample evidence that adherence to HAART improves health outcomes and increases life expectancy (Nam et al., 2008; Reynolds, 2011; Volberding & Deeks, 2010). Weaver and colleagues conducted a prospective study and examined the role of psychosocial factors (denial, social support), quality of life and HIV medication regimen on HIV treatment adherence. Participants were recruited from several medical centers across the United States. They found that use of denial was significantly correlated to non-adherence of HIV antiretroviral medication. Further, in a randomized control trial with HIV positive women on HAART investigating how coping strategies relate to quality of life. The results indicated that denial was related to poor treatment adherence and lower quality of life (Weaver et al., 2004).

More recently, Konkle-Parker and colleagues (2008) qualitative study sought to examine the barriers and facilitators to HIV treatment adherence in a predominantly minority population in Mississippi. As one respondent said "I was mad, and I was upset, and I was in denial. And it took me five years to tell anybody that was close to me. So I kept that to myself for a long time, and I was very angry. Right now, I still don't take [the medicines] like I should" (pg. 4). Findings showed that denial was one of the main reasons for not adhering to medication regimens and disclosure of HIV status to others (Konkle-Parker et al., 2008). Adherence to HIV medication is important to keep PLWHA virally suppressed, but if they are not engaged in HIV medical care they cannot benefit from these life-preserving medications.

Denial and engagement in HIV medical care

Denial and delay in HIV medical care had been studied (Pollini et al. 2011, Raveis, Siegel& Gorey, 1998; Siegel, Schrimshaw & Deal, 1999) and found to be a significant predictor of PLWA delaying engagement in HIV medical care. Pollini et al. (2011) conducted a comparison community study in California with PLWHA, who had delayed entering HIV medical care for 3 months after diagnosis, and persons who were currently in care to determine significant predictors of entering HIV medical care. HIV treatment educators administered surveys that contained questions about demographics, barriers to care (predisposing, enabling and need factors) and sexual and drug risk behaviors. Findings showed significant differences in denial between the two groups. Many who had never been in care reported denial (i.e. "Didn't want to think about being HIV positive") as a barrier to initiating medical care. They were also three times more likely to not be engaged in HIV medical care as compared to persons currently in care (Pollini et al., 2011).

This study provides support that denial is an important barrier to assessing HIV medical care for the newly diagnosed individuals. In addition, the researchers also suggested that participants did not tell others about HIV status for fear of discrimination hints that stigma is also a barrier to delaying entering HIV medical care. While, denial was assessed by asking participants one question that implicated they were in denial, more research is needed to examine the role of standardized measures to determine the level of denial and its influence on PLWHA's decision to engage in HIV medical care.

In another study that examined the barriers and facilitators to engagement in HIV medical care among HIV positive persons living in the Deep South. Researchers conducted 130 in-depth interviews with PLWHA who delayed entry into HIV care and/or had a gap in medical care. They found that denial was reported in the majority of the sample as a barrier to entering care and approximately one quarter said that denial was a barrier to remaining engaged in medical care (Konkle-Parker et al., 2011). The above studies corroborate with previous studies that HIV is a highly stigmatizing condition and that denial and HIV stigma are two important factors to consider as barriers to engagement in HIV treatment and medical care.

Relationship between Denial, HIV Stigma and engagement in HIV medical care

Studies have supported that the two psychosocial factors HIV stigma and denial are associated with HIV medical care (Beer et al., 2009; Konkle-Parker, et al., 2008; & Sayles, et al., 2007). There are a limited number of studies that have examined how the two are associated with engagement in HIV medical care. This could be because the majority of the studies have been qualitative and point to the need for further research in this area. Sayles et al. (2007) conducted a study with PLWHA (men and women) in Los Angeles, CA to explore the impact of stigma on health and health care. Participants were asked about their experiences and perceptions with HIV stigma and how it affects health and healthcare. Stigma and negative experiences within the health care environment caused participants to delay or drop out of care completely. They also reported that many participants were in denial after receipt of HIV diagnosis, and described using denial to cope with HIV stigma (Sayles et al., 2007).

Additionally, the CDC sponsored “Not in Care Study, a qualitative study conducted with PLWHA who were not utilizing HIV medical care 6 months after diagnosis. Participants were recruited from community based organizations and health departments in 5 states across the U.S. (IN, NJ, NY, PA, WA). A total of 37 PLWHA participated in focus groups. They were questioned about personal barriers to engaging in HIV medical care after HIV diagnosis. All participants stated that HIV stigma was a barrier to utilizing HIV medical care. Specifically, perceived HIV stigma from medical providers where some refused to continue to provide care to patient after learning of HIV status. For this reason, participants decided not to engage in HIV medical care. Further, in all focus groups denial and disbelief of HIV diagnosis was mentioned also as a reason for not engaging in HIV medical care (Beer et al., 2009). Consistent with previous studies engaging in medical care was a reminder of their HIV status, as they didn’t want to think about it and hoped it would go away. This study suggests that the perception of HIV stigma may lead a person to use denial of HIV disease and consequently not seek medical care. Moreover, it is important to note that this was a nationwide study and the major barriers to engaging in HIV medical care among all participants were the psychosocial factors (denial and HIV stigma). More research is needed to discover how denial interacts or relates to HIV stigma among newly diagnosed persons with HIV and those persons who do not remain engaged in HIV medical care.

In another qualitative study, 40 HIV positive women, from rural Alabama, were recruited from community-based HIV organizations to explore perceived barriers to engaging in HIV medical care. The respondents were asked to explain their experience with HIV medical care. Five types of barriers emerged: personal, social, financial, geographic and the health care system. Of the five barriers, denial and HIV stigma were the most frequently mentioned as barriers to accessing HIV medical care. The women stated that denial was the most common response to their HIV diagnosis, which led them further away from care, as they did not want to think about their diagnosis. In addition, their other concern was HIV stigma specifically how they were perceived or treated by others finding out about their HIV status. These women did not want to be seen by others accessing HIV medical care. The authors suggested that to examine these barriers further, the Andersen Model of Health care utilization would be an appropriate model to show clearly how these barriers affects PLWHA's engagement in HIV medical care (Moneyham et al., 2010).

More recently, Dr. Lisa Fitzpatrick, an infectious disease HIV physician, from Washington, DC, wrote an article, explaining that what she has been witnessing in her interactions with her patients, and what she believes need to be done to address this lack of engagement in HIV medical care. One point she made is that, what is lacking in research is the examination of denial, stigma, and shame when it comes to why PLWHA are not engaging in HIV medical care. Further, she states that to adequately address the gaps in care that are seen along the HIV continuum of care and the HIV treatment cascade that these psychosocial factors will need to be addressed (Fitzpatrick, 2013).

In summary, these studies underscore the need to consider how denial and perceived HIV stigma not only affects treatment adherence but also whether PLWHA will engage in HIV medical care. This study will add to the literature, as it sought to identify quantitatively, if in fact denial and perceived HIV stigma are the major barriers that cause PLWHA not to engage in HIV medical care after diagnosis with HIV.

Measurement of Denial

With many of the chronic illnesses that require medical care the measurement of denial can be accomplished in the clinical and community settings. First, there is clinical judgment /observation, where the physician believes that the person is not acknowledging their diagnosis and they report that the person is in denial. Second, there are clinical semi- structured interviews administered by clinical staff to patients (e.g. Levine Denial of Illness scale). This type of measurement entails the clinical staff going thru a series of questions and scoring them to determine if the patient is in denial about their diagnosis (Levine et al., 1987). Third, the patient can self-report their psychological state by completing questionnaires that reveal whether they are in denial about the illness. Lastly, a behavioral indication of denial can also be when a person delays seeking medical care after learning of diagnosis of a chronic illness (Goldbeck, 1997; Livneh, 2009).

For this study the assessment of denial was measured by a self- report measure. There are a few measures that have examined how PLWHA cope with their HIV status. These include: the Illness Behavior Questionnaire (IBQ), Ways of Coping Scale, and the Coping Orientation to Problems Experienced Scale (COPE). The Illness Behavior Questionnaire was developed by Pilowski and colleagues, and examines a person's perception of their illness. This 62-item scale contains seven subscales that measure: denial, hypochondriasis, disease conviction, affective inhibition and disturbance, irritability, and psychological vs. somatic perceptions of illness (Merz et al., 2013; Pilowski & Spence 1975). This 4-item denial subscale was not chosen as it measures life worries, and has not been used frequently with PLWHA.

The second measure that has been used to measure denial is the Ways of Coping measure developed by Folkman and Lazarus (1985). This scale measures perceptions of how people cope with stressful situations. This is a 66-item scale has seven subscales: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape avoidance, and positive appraisal. The subscale contains one item denial that measures denial. This scale has been used with PLWHA, but measures escape and avoidance more so than denial (Folkman & Lazarus, 1985).

The last scale examined to measure denial was the COPE- denial subscale. This measure was utilized to measure denial over the Ways of Coping and Illness Behavior Scale because it appears to be a more face-valid measure of denial of HIV status. This scale is also parsimonious, reliable and has used with PLWHA in other studies (Weaver et al., 2004; Weaver et.al, 2005).

Theoretical Framework

There are a few theories that have been proposed to study HIV/AIDS and health care utilization for PLWHA. These include the Health Belief Model (HBM), Biopsychosocial Model, and the Andersen behavioral model of Health care utilization (ABM) (Mkanta & Uphold, 2006). The theoretical framework that was used for this research study is the Andersen Behavioral Model of Health care Utilization, which was originally developed by Andersen in 1968 to determine how families utilize health services (Andersen, 1995).

According to the ABM, health care utilization can be influenced by three factors-Predisposing, Enabling and Need (PEN). The predisposing factor refers to demographic variables (e.g. age, gender). The enabling factors refer to resources that would help a person access health care (e.g. income, health insurance), and need factors refer to a persons perceived needs that will help them enter medical care (Andersen, 1995).

The Andersen Behavioral Model of Health Care Utilization has been used to predict outcomes such as cervical cancer screening (Andrasik, Rose, Pereira & Antoni, 2008), Complementary and Alternative Medicine (CAM) use (Brown, Barner, Bohman, & Richards, 2009), and long-term care use (Bradley et al., 2002). The ABM has also been adapted to include psychosocial factors. Bradley and colleagues (2002) in a qualitative study adapted the ABM by adding psychosocial factors (e.g. attitudes, knowledge, social norms and perceived control) to explain race/ethnicity differences in long term care use. They found that adding psychosocial factors to the ABM model enhanced the utility of the model, and allowed for a more complete understanding of race /ethnicity differences in long term care use (Bradley et al., 2002).

The original Andersen Behavioral Model has also been used to predict HIV treatment adherence for PLWHA. Several studies have used national datasets such as the AIDS Cost and

Services Utilization Survey (ACSUS) and the more recent HIV Cost and Services Utilization Survey (HCSUS) to predict HIV treatment adherence. The two datasets were both longitudinal studies that used interviews, medical and billing data to determine medical cost and use by persons living with HIV/AIDS. Smith & Kirking (1999) applied the ABM to the ACSUS data to determine if predisposing, enabling and need factors were associated with use of HIV medications. Results indicated that being female, between the ages of 15-24, and having a history of hospitalization predicted lower odds of HIV medication use. Conversely, being African American, having health insurance and a usual place of care increased the odds of HIV medication use (Smith & Kirking, 1999). In another study by Smith, Boyd and Kirking (1999), also using the ACSUS data they examined the association of predisposing, enabling, and need factors with alternative medication use to treat HIV disease. They found that African Americans were less likely to use nonprescription drugs, compared to whites, enabling factors were associated with illicit substance use and need factors were associated with non-prescription drugs and vitamin use by PLWHA (Smith, Boyd and Kirking, 1999). The ABM model is an adequate theory to examine HIV treatment adherence and the use of non-prescription medication with PLWHA. Furthermore, it can be used with national data to examine PEN factors. These studies confirm the utility of the theory. The limitation of these studies is that many did not include any health belief or attitudinal variables about HIV treatment.

More recently, Luseno et al (2010) examined health service utilization among HIV positive women in South Africa with a history of sexual and substance abuse risk factors. Their findings suggest that denial of HIV status is a major barrier for women not utilizing health care. Certainly, this study provides evidence of the need to adapt the ABM to include denial as a predictor of HIV/AIDS medical care engagement (Luseno et al., 2010). For this research study, an adapted version of Andersen Behavioral model of healthcare utilization was used to determine predictors of engagement in HIV medical care by PLWHA. This adapted model included the psychosocial factors (e.g. denial and perceived HIV stigma). As mentioned above, adding psychosocial factors to the ABM has proved beneficial to the explanation of care outcomes (Bradley et al., 2002). This study will add to the literature by examining how these important psychosocial factors may affect a PLWHA's decision to engage in HIV medical care.

Chapter 3: Methods

Study Context

Participants in this study were recruited as part of a larger project called the Positive Pathways (PP). In 2011, Positive Pathways a 4-year evidence-based intervention, created by Washington AIDS Partnership (WAP) and the Institute Public Health Innovation (IPHI), was started. Positive Pathways uses community health workers to address barriers to HIV medical care for PLWHA in the metropolitan Washington, DC area. The main goals of Positive Pathways are (1) to evaluate whether the Community Health Worker model reduces barriers to HIV medical care as well as improve the healthcare system in Washington, DC for PLWHA; and (2) to reduce community HIV viral load in the targeted communities (Wards 5-8).

CHW's received formal training in an eight-month community health worker certificate-training program at the University of District of Columbia. The CHW Certificate program provided them with the tools to be health advocates and educators in their communities. They also received instruction on how the healthcare system works, and appropriate ways to address chronic illnesses such as HIV/AIDS, and diabetes.

In 2012, the present research study became embedded into the Positive Pathways project. The investigator added three standardized scales measuring denial, perceived HIV stigma and barriers to care to the existing baseline assessment.

CHW Training for Data Collection on this Study

The investigator had nothing to do with prior training of CHWs or their management and oversight at their respective organizations. For the purposes of this study, the investigator trained the CHW's on administering the denial, perceived HIV stigma and barriers to care scales during one of their monthly trainings to ensure uniformity. Before data collection began on this study, the investigator trained the CHWs on administering the measures. At the training, the community health workers received the list of the questions as well as the questions downloaded on their ipod device. Each measure was explained to the CHW first by going over the instructions and then each item on all three scales. There was a question and answer period to answer any questions about the items or language that may have been unclear. The CHWs practiced administering each measure. At the end of the training the CHWs understood each measure and they were able to successfully administer them to another person.

Study Design

A **prospective cohort design** was used to examine the relationship between denial, perceived HIV stigma and engagement in HIV medical care. This design was appropriate as the outcome variable (engagement in HIV medical care) and was measured after 90 days of enrollment in Positive Pathways. HIV positive, African Americans over the age of 18 were recruited into Positive Pathways from multiple HIV care and service organizations. After enrollment, participants completed a baseline assessment to provide data on demographic, clinical factors, needs, and barriers associated with engagement in HIV medical care. Specifically for this dissertation research, two psychosocial constructs were added (denial and perceived HIV stigma) and one structural construct (barriers to care), to the baseline assessment. Participants also completed 45 and 90-day follow-up assessments. Community health workers administered all three assessments. Figure 3.1 below represents the study design and participant flow in the study.

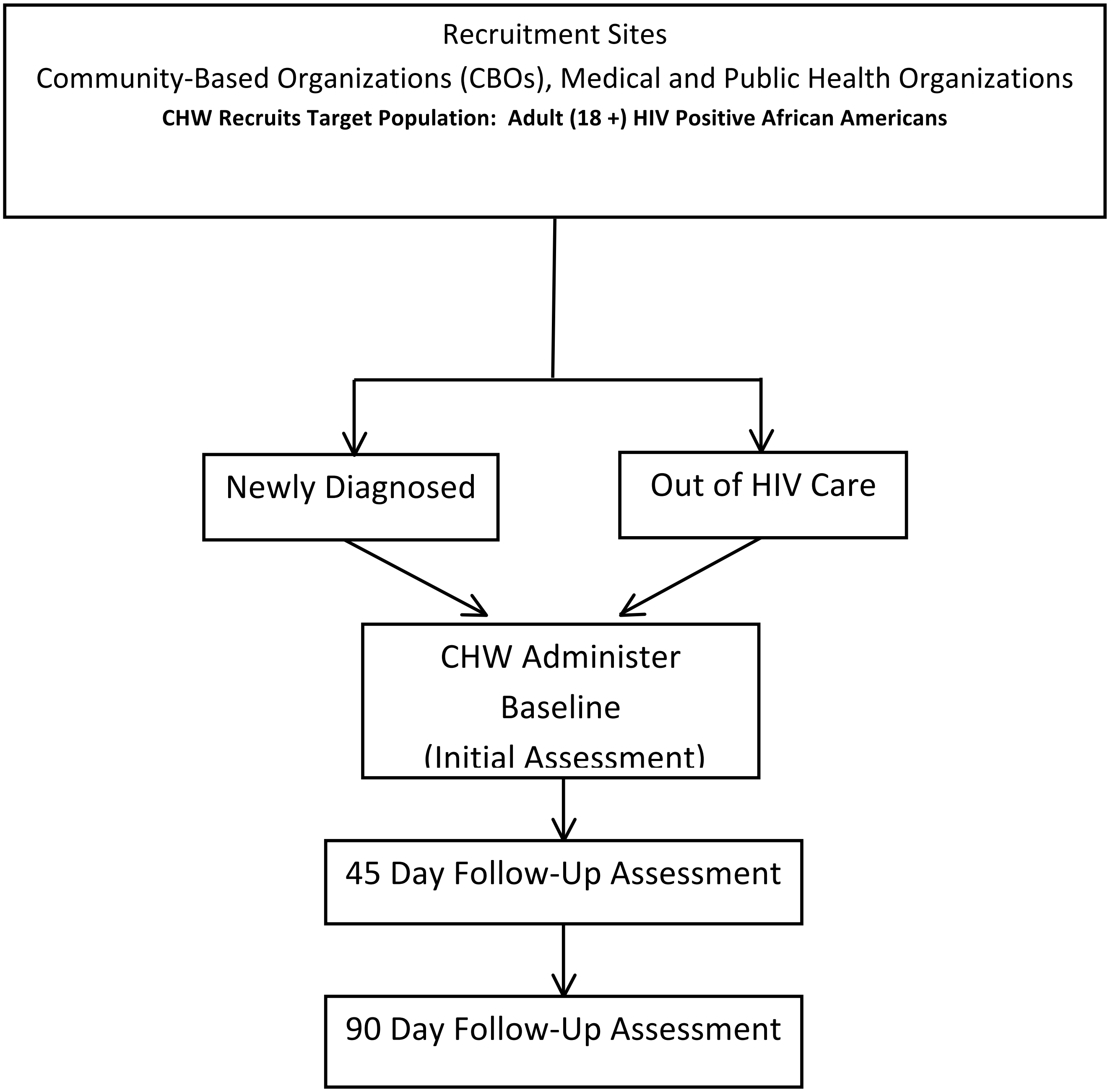


Figure 3-1 Research Study Design

Data Collection Sites

The study was conducted in metropolitan Washington, DC. The District of Columbia has the highest rate of AIDS diagnosis at 112.5 per 100K persons, which is 10 times the U.S rate for AIDS diagnosis (Kaiser Family Foundation, 2012). Also, it is the metropolitan area with the highest HIV incidence rates in the United States (CDC, 2011). DC is divided into eight geopolitical wards. Figure (3.2) displays the eight wards in DC and the corresponding HIV infection rates. Residents of wards 5-8 are disproportionately affected by the HIV/AIDS epidemic as they have the highest rate of persons with HIV/AIDS in Washington, DC (HAHSTA, 2011).

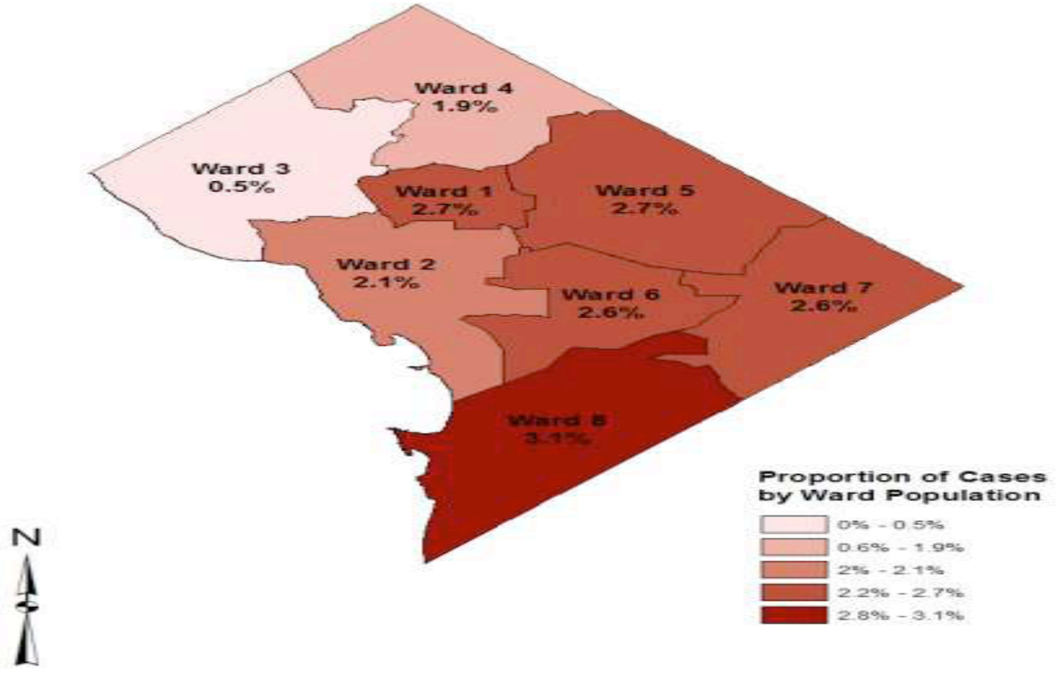


Figure 3-2 Map of Washington DC with HIV rates by ward

Source: Proportion of Adults and Adolescents Living with HIV by Ward, District of Columbia, 2010 DC DOH HAHSTA – 2011 annual report

Participants were recruited from six participating sites affiliated with the Positive Pathways project located in Washington, DC. The participating sites fall into four different types of HIV services organizations: primary medical care, community-based, managed care and public health organizations. These organizations provide and /or link persons living with HIV/AIDS to HIV medical care and services. The sites included: Family & Medical Counseling Services, Inc., Max Robinson Center of the Whitman-Walker Clinic, The Women's Collective, Our Place DC, AmeriHealth Caritas and , and Unity Health Care.

These sites signed a Memorandum of Agreements' (MOAs) with the Institute for Public Health Innovation (IPHI) to participate in the Positive Pathways project. The trained peer Community Health Workers (CHWs) were employed at the participating organizations and worked within their sites to recruit participants. Many of the organizations were located in communities with the highest HIV/AIDS incidence (wards 5-8). Table 3.1 below provides information about the study sites-organization type, ward and the number of CHW's assigned to each location.

Table 3-1 Characteristics of Positive Pathways Participating Organizations

Site/organization	Type	Ward	Number of CHWs
Family Medical Counseling Services	Community-based organization	8	1
The Women's Collective	Community based organization	7	1
Our Place- DC	Community-based organization	6	1
Unity Healthcare	Primary Medical Care	7	4
AmeriHealth Caritas	Managed Care Organization	2	2
Whitman Walker Health	Primary Medical Care	1	1

Family Medical Counseling Services (FMCS). FMCS is a community health center serving the District of Columbia community for over 25 years. One of their main goals is to serve residents located primarily in the neighborhoods east of the Anacostia River. They specialize in providing comprehensive medical care for HIV/AIDS positive persons through all stages of illness. Their mission is to promote the emotional and physical health of families and individuals, regardless of income and social status, and maximize their quality of life. They provide medical care and services to approximately 1000 PLWHA a year.

The Women's Collective (TWC). TWC is the only community based organization in Washington DC focused on meeting the needs of women and girls with HIV/AIDS. Since its inception back in the early 1990's as a support hotline for women diagnosed with HIV, TWC has become a comprehensive HIV care and support services organization. They have trained women to become advocates, provide prevention, care and treatment and support services and to address the social determinants of health associated with HIV/AIDS.

Our Place-DC. Our Place DC was a community- based organization in Washington DC dedicated to helping currently and formerly incarcerated women as they transition out of the criminal justice system. The HIV Services department helped connect their HIV-positive clients to care and services.

AmeriHealth Caritas DC. AmeriHealth Caritas formerly Chartered Health Plan is the oldest Medicaid Managed Care Organization in the Nation's Capital. They currently serve over 100,000 Medicaid eligible and uninsured recipients of the District of Columbia. AmeriHealth insures approximately 800 PLWHA.

Whitman Walker Health (WWH). WWH is a community health center that has been providing HIV medical care for nearly four decades. Their reputation for providing high quality culturally competent care to approximately 3,000 patients who are living with HIV/AIDS is known locally, nationally, and internationally.

Unity Health Care. Unity Health Care, Inc. (Unity) was founded in 1985 as the Health Care for the Homeless Project providing primary health care services to homeless individuals and families who reside in local emergency shelters or on the streets of the District of Columbia. Unity offers a full-range of primary health care services that reach every facet of the community, including the homeless, under/uninsured, the elderly, and persons living with HIV/AIDS.

Selection Criteria and Recruitment

Selection Criteria

The primary population for recruitment into Positive Pathways consists of HIV positive women and men obtaining HIV medical care and services in Washington DC. Purposive sampling procedures were used because participants were diagnosed with HIV, possibly affiliated with the participating organizations and referred to the community health worker. Participants were African -American, 18 years of age or older, who were newly diagnosed with HIV (i.e. diagnosed with HIV for less than 3 months prior to enrollment) or had been out of HIV medical care for at least 6 months. The Positive Pathways program had eligibility criteria that guided the CHW's decision about which clients to classify as study eligible at enrollment into the study (e.g. newly diagnosed, out of care, and in care). The community health worker referred to the classification criteria before assigning participants to a particular client type. The participants that were classified as newly diagnosed and out of care were used in this research study. Participants who did not consent to participate in Positive Pathways project and persons who were in continuous HIV medical care were ineligible for the study (i.e. participants who had 2 or more medical visits with a HIV provider at least 2 month apart during the prior year) (HRSA, 2011).

Recruitment and Data Collection

Community Health workers conducted one-on-one interviews with participants using three (i.e. baseline, 45-day and 90-day) assessments. Recruitment for this study was conducted between August 2012 and July 2014. The CHWs used multiple recruitment mechanisms to identify potential participants. These included: internal referrals from within their agencies (i.e. case managers, nurses and physicians), pharmacy records, street and peer outreach. PLWHA who were seeking care at participating medical and community-based sites were screened for eligibility and referred to the community health workers.

The Community Health workers screened eligible persons for Positive Pathways and confirmed their willingness to participate in the study followed by enrollment into Positive

Pathways. Enrollment into Positive Pathways occurred primarily at the CHWs participating organization. After enrolling participants, each were assigned a unique client identification number that was used on all assessments instead of any Protected Health Identifiers (PHI). At enrollment, CHW's conducted one-on-one interviews with participants that involved: First, an overview of Positive Pathways project. Second, participants were given information about what it means to live with HIV. Next, participants signed an informed consent and confidentiality form and finally, participants completed the baseline assessment. After completion of baseline assessment CHWs were to offer to help clients arrange medical and case management appointments.

The community health worker was responsible for contacting enrolled participants by telephone to complete the follow-up assessments. The follow-up assessments were completed 45 and 90 days after enrollment. Clients had the option of completing the assessments in person or over the telephone. The follow-up assessments were conducted in the same manner, with the CHWs reading the questions verbatim and entering responses into the iPod touch to be uploaded after completion to the iForm Builder server.

Assessments were administered by the CHW using the iForm ES application (app) downloaded onto an iPod touch. In July 2012, the researcher was instrumental in converting the Positive Pathways assessments from paper to mobile technology using iFormBuilder mobile platform^{TM}. Each CHW had the iForm ES app with the assessments (i.e. baseline, 45-day, and 90-day follow-up) downloaded on their iPod touch device. The iPod touch was password protected and the iForm ES application required a user name and password that was unique to the CHW.

To complete an assessment with a participant the CHW logged into the iForm ES app and chose the appropriate assessments (i.e. baseline, 45-day or 90 day follow-up). The CHW read each question verbatim to participants and entered their responses into the iPod touch. Participants were told that they can refuse to respond to any question at any time during the assessment. After completion of the assessment the CHW saved and submitted the assessment. The data were then transferred via Secure Sockets Layer (SSL) encryption to the iForm Builder server.

Measures

The measures used in this study were guided by (1) the national evaluation measures for Positive Pathways; (2) thorough review of the literature on psychosocial variables associated with persons delaying entering and engaging in HIV medical care and (3) the theoretical model (Andersen Behavioral Model of Health Care Utilization).

Baseline Assessment

The baseline assessment was administered after enrollment into Positive Pathways. A copy of the baseline assessment is presented in Appendix C. This assessment measured:

(1) Predisposing variables (e.g. demographic variables – age and marital status)

(2) Enabling (e.g. income and health insurance)

(3) Need (e.g. client reported needs and health status)

(4) Psychosocial measures (e.g. denial and perceived HIV stigma)

Psychosocial Constructs

Perceived HIV Stigma. Perceived HIV stigma was operationalized as a fear of rejection, personal experiences and perceived negative consequences of other people knowing a person’s HIV status (Berger, Ferrans, & Lashley, 2001). The Berger’s HIV stigma scale is a 40-item scale that measures stigma perceived by PLWHA. The scale consists of 4 subscales (1) personalized stigma, (2) disclosure, (3) negative self-image, and (4) public attitudes. The personalized stigma subscale is composed of 18 items, and was used to measure perceived HIV stigma in this study. Participants were asked” how much they agree with the following questions about experiences, feelings, and opinions about how people with HIV feel and they have been treated”. Sample items include:

(1) People seem afraid of me because I have HIV

(2) I feel set apart, isolated from the rest of the world

(3) I have lost friends by telling them I have HIV

Items were rated on a 4-point Likert scale with response options ranging from 1 (strongly disagree) to 4 (strongly agree). Additional response options of don’t know, refused, and I haven’t told anyone were added, as some participants may not be able to answer the questions. Prior to addition of Berger’s HIV stigma scale, the assessments included stigma items which many participants were leaving blank. After consulting with the CHWs, it was discovered that many clients were not answering the stigma items because they had not disclosed their HIV status to others. Because of the previous experience with stigma items on the baseline assessment, this led the researcher to modify the Berger’s perceived HIV stigma scale by adding the additional response item” I have not told anyone”.

Because of this, 46 % (n=104) of the participants responded “I have not told anyone” to at least one item on the perceived HIV stigma scale (see Appendix F). The number of participants who completed the perceived HIV stigma scale was 120 and this group of responders was classified as the “disclosed sample”.

Perceived HIV stigma scale. The total number of participants who answered any one of the items on the perceived HIV stigma scale was 168. A review of the frequencies indicated that 104 cases indicated that they had not disclosed their HIV status and hence could not answer the questions. Hence, there was much missing data. This posed a dilemma for the analysis. For example, some participants answered no items, while others answered only 4 items and others may have answered all 18 items. Using the mean scale of this sample in the analysis would be imperfect, because the mean scale would not be an accurate depiction of perceived HIV stigma in this sample. With the great number of missing items, and variable missing across cases, a scale average was considered to have too much opportunity for a large error component as part of the variance and this was deemed unacceptable.

To resolve the problem related to the high number of missing data, the HIV stigma scale was only calculated for those persons who had disclosed their HIV status to others. The perceived HIV stigma scale was created using only persons who did not answer “I have not told anyone” to any items on the perceived HIV stigma measure. The number of participants used to create this scale was 120. The 18 items were averaged to create the perceived HIV stigma mean scale (disclosed).This scale was a better representation of perceived HIV stigma in the sample than a summative scale would have been because of the large amount of missing data, and less error in creating scale scores based on a variable number of completed items. The perceived HIV stigma mean scale (disclosed) was used in all univariate, bivariate and multivariate analysis. The possible range of scores on the perceived HIV stigma mean scale was 1 to 4. Higher scores indicate greater level of perceived HIV stigma by participants. For this study the alpha reliability for the disclosed sample was .97.

Denial. For the purpose of this study, denial was operationally defined as "refusal to believe HIV diagnosis or trying to act as though HIV is not real". Denial can be used as a defensive coping mechanism to protect the person from feeling or dealing with HIV diagnosis. Carver and his colleagues developed the 60-item Coping Orientation to Problems Experienced Scale (COPE) (Carver, Scheier, & Weintraub, 1989). The COPE is a multidimensional scale that measures 13 different aspects of coping (active coping, planning, suppression of competing priorities, restraint coping, seeking instrumental and emotional support, positive reinterpretation, acceptance, turning to religion, venting, behavior disengagement, mental disengagement, alcohol-drug disengagement and denial).Denial of HIV status was measured using the (COPE) - denial subscale. Participants were asked "how often in the past month you have used each of the following to cope with your HIV". The scale contains the following four questions:

1) I say to myself "this isn't real"
2) I refuse to believe that it has happened
3) I pretend that it hasn't really happened
4) I act as though it hasn't even happened

The 4 items were measured on a 4-point Likert scale with response options ranging from 1(not at all) to 4(often). Additional response options of don't know and refused, were added as some participants may not be able to answer the questions. The 4 items were averaged to create a denial mean scale. Two denial mean scales were created for the total and disclosed sample. The possible range of scores on the denial mean scales is 1 to 4. Higher scores indicate greater use of denial by participants. The denial mean scale score was used in all bivariate and multivariate analysis. The internal consistency for the scale has been previously been reported to be .71 and test-retest reliability .54 (Carver, Scheier, & Weintraub, 1989). In the present study, Cronbach's alpha for the total and disclosed sample was .93 and .88 respectively.

Disclosure Variable. A binary disclosure variable was created from the perceived HIV stigma measure to capture disclosure status within this sample. The perceived HIV stigma scale included the response item "I haven't told anyone". Some participants were not able to answer certain questions on the scale because the items did not apply to them (e.g. I have lost friends by telling them I have HIV). First, the disclosure variable was created by examining the questions on the measure that had highest number of participants who responded, "I have not told anyone". Second, a dichotomous variable was created to capture any participant who responded, I have not told anyone and they were classified as non-disclosed (n=104). All other participants were classified as disclosed (n=120). Finally, the lack of disclosure of HIV status among participants required that the analysis be completed with two different samples, the total and disclosed. The disclosure variable was used in the analysis specifically with the total sample and the perceived HIV stigma scale was used in the disclosed sample analysis.

Predisposing Factors. They included demographic information (e.g. age (continuous), marital status (e.g. Single/Separated/ Divorced/Widowed and Partnered/Married, education (< HS education, HS education/GED, and Some College or Tech School/College Degree or Higher).

Enabling Factors. Participants responded to questions about enabling factors. The items included questions about income (e.g. <$15 000 and >$15,000), health insurance (e.g. Yes or No), employment status (e.g. Unable to work, Unemployed, able to work, and Unemployed, unable to work), and if they had a medical provider/home (Yes or No).

Need Factors. Participants responded to questions about need factors. The items included questions about client reported needs (continuous), client reported barriers to care (continuous), quality of life(e.g. Poor, Fair, Good, Very Good, and Excellent), and clinical indicators(e.g. CD4 and HIV viral load).

Open–ended Needs. The participants' self- reported needs related to obtaining HIV medical care and services. Participants were prompted by the question "What services do you currently need?" The CHW did not read any of the responses, but recorded the spontaneous needs mentioned (e.g. substance abuse treatment, housing, food). A total of 14 needs were possible for participants to list. The 14 need items were dichotomized, and if a participant did not list a need it was coded as 0 and a yes response was coded as 1. The responses were summed and averaged to produce a continuous scale from 0 to 9. Higher scores indicate greater number of needs to accessing medical care.

Open-ended Barriers to Care Items. Participants were asked to list what barriers they face getting into HIV medical care **"**Often people with HIV face barriers to getting HIV care"? What factors make it hard for you to get care?" The CHW recorded only what the participants mentioned as barriers (e.g. fear denial, stigma, and homelessness). A total of 16 barriers were used to record their responses. The 16 barriers items were dichotomized. If a participant does not list a barrier it was coded as 0 and a yes response was coded as 1. The responses were summed and averaged to produce a continuous scale from 0 to 8. Higher scores indicate greater number of barriers to accessing medical care.

Barriers to Care Scale (BAC). The BAC scale was used to assess participants' perceptions of the availability of HIV-related services. The 12-item measure contains four subscales that measured geographical, economic, community stigma and structural barriers that prevent PLWHA from accessing HIV medical care and social services. (Heckman, Somlai, Otto-Salaj, Perters, Walker, Galdabini, & Kelly et al., 1998) Participants used a 4-point Likert scale to respond with response options ranging from “no problem at all” (1) to “major problem” (4). Additional response items included don’t know and refused which were coded as missing.

A modified 8-item version of this scale was created and used because the four items pertaining to community stigma and work environment knowledge were removed from the barriers to care scale. These items contained high numbers of missing values, where participants answered ‘refused’ or ‘don’t know’. This lead the researcher to believe that participants did not fully understand the questions or that they did not apply to participants. The 8 items were averaged to create the barriers to care scale. Higher scores indicate greater perceived barriers to receiving HIV medical care and services. The modified 8-item scale was used in all subsequent analysis. Previously the scale has adequate internal consistency in previous studies .86 and.93 (Heckman et al., 1998; Heckman, 2003). For this study the internal consistency was .81. The data analysis for this measure and engagement in HIV medical care can be found in Appendix F.

There were two scales used to measure barriers to care in this study, one was an open-ended spontaneous response to barriers and the other a standardized barriers to care scale. The standardized barriers to care scale was added to objectively measure common barriers to care faced by PLWHA. According Reja and colleagues (2003), there are advantages and disadvantages to both types of data collection, but using a standardized measure accounts for large item non-response that can occur with open-ended questionnaires (Reja et al., 2003). Neither scales were significantly related to engagement in HIV medical care and were not used in the multivariate analyses.

Quality of Life. Participants were asked about how they feel about their general health. The response choices, included (1) poor to (5) excellent. Additional response items included don't know, and refused and they were coded as missing.

Biological Indicators. Participant's most recent CD4 count and HIV viral load were obtained from assessments and/or patient medical records, as these indicators are important indicators of HIV disease progression. If this information was not included in the baseline assessments then CHWs retrieved the information from the patients' medical record.

An outlier analysis was conducted for HIV Viral load to make sure accurate associations were presented and there were no observations that have a large influence on the findings allowing for inaccurate interpretation of results. To detect any outliers in the HIV viral load values first, the data were organized in ascending order, second, the 25th (Q1) and 75th (Q3) percentile of data were obtained, third, the interquartile range was calculated (Q3 – Q1), fourth, this interquartile range (middle 50% of the data set) was used in the outlier labeling formula to calculate the upper and lower bound criteria. The Outlier labeling formula below was used to identify any upper and lower values that were considered outliers (Hoaglin &Iglewicz, 1987; "Outlier Labeling Rule", 2012).

Upper = Q3 (22783) + (2.2*(Q3-Q1)) 22708)

Lower = Q1 (75)-(2.2 * (Q3-Q1)) – 49883) (no lower bound outliers)

Any scores lower than the lower bound and greater than the upper bound were considered outliers. Three participant's had HIV viral loads greater than the upper bound and were categorized as outliers and were recoded as missing.

Follow-up Assessments

Forty-five day and 90- day assessments. The community health worker contacted the participants to schedule an appointment to administer the follow-up assessments. The 45 and 90-day assessments were used to determine dates of HIV medical care visits since enrollment in the study. The follow-up assessments were conducted in the same manner as the baseline assessment. The only variables used from the follow-up assessments were the questions related to the dependent variable.

Dependent variable

Engagement in HIV medical care. The CDC recommends that PLWHA enter medical care within three months of diagnosis (CDC, 2001); and the NHAS has set national goals of linking 85% of PLWHA within three months of diagnosis (NHAS, 2010). The main outcome for the study is the participant's engagement in HIV medical care. Engagement in care was operationalized as having at least 1 HIV medical visits within 90 days of enrollment in the study. Participants were surveyed at 45 and 90-day follow-up to determine if they had completed a HIV medical visit. The following questions were asked on the 45-day assessment, (1) Have you been to a provider with prescribing privileges within the last 30 days? (2) What was the date of your first HIV medical visit since we first met? The medical visit question on this assessment asked about the last 30 days even though recorded on the 45 day assessment. The 90-day assessment asked the following questions, (1) have you been to a medical visit with a provider who can prescribe medicine in an HIV care setting? (2) What was the date of your HIV medical visits?

Data for the dependent variable was based on self-reported attendance with an HIV primary care provider. This information was obtained from the 45, 90-day assessments, and medical record review by the CHW to determine if participant had an HIV medical appointment. CHW medical record review was used only when there were no self-reported data on the assessments. It is expected that both self report and medical record review would contain sources of error. For example, participants may falsely report having a medical appointment because of social desirability or recall bias as they may not recall the exact dates of the appointments.

The follow-up assessments at two time points (45, 90-day) were necessary because of a concern about completion of this data collection and lack of completion limiting power in the sample size to detect a difference between the two groups. Participants may have been lost to follow-up after 45 days, thus the 45 day assessment was used to be certain that their outcome data were captured, if they did not return for the 90-day follow-up assessment. Also, there was a concern that CHWs reporting medical record review data at 90 days may be unreliable in their medical record review over all 90 days, but what was found is that they reported the 45-day medical visit information in the 90-day assessment.

Engagement in HIV medical care was calculated by subtracting the baseline date from the dates of the HIV medical visits. If the participant had a medical visit within 90 days after the baseline assessment they were labeled as engaged (1), and if a participant did not have any medical appointments in the 90 days after enrollment they were considered non-engaged (0). Participants who were lost to follow-up during the 90-day follow-up period up were coded as 0-no engagement in HIV medical care. This decision inflates the no-engagement category, but was done because it was assumed that if the participants were lost to follow- up then they were not receiving HIV medical care. Approximately 13 participants were considered lost to follow-up (See Figure 4-1).The 45 day and 90 day assessments are provided in Appendix D.

Data Management

Data was uploaded by CHW's to iFormBuilder.com. A second version of the data set void of all Health Insurance Portability and Accountability Act (HIPPA) designated identifiers was created for the researcher to be used for analysis in this study. Data from the version- 2 was imported into SPSS 21.0 for data analysis. A codebook was developed and missing data analysis was conducted.

Missing Data

Data were analyzed for missing data. The scales included the response options: "refused and don't know". In addition, the perceived HIV stigma measure included the response option, I have not told anyone. Scale items that included the above responses or had missing data were coded as missing in SPSS and therefore excluded from the data analysis.

Data Analysis

Data analysis was performed using SPSS 21.0 (IBM Inc., Armonk, NY) with two-tailed test and an alpha statistical significance level of 0.05 for all tests.

Data Analysis Plan

To answer the research questions and hypotheses the following analyses were conducted. Descriptive Statistics were used to examine the distributions for all predisposing, enabling and need variables (e.g. age, denial, perceived HIV stigma) to explain characteristics of study population. For continuous study variables the mean, standard deviation and range were calculated (age -mean /SD, range) and for categorical variables (e.g. education, marital status, income-N, frequencies %) were calculated. Cronbach's alpha was performed to obtain the reliability of psychosocial scales, descriptive statistics, bivariate (t-test, chi-square analysis); multivariate logistic regression and interaction analysis were performed as described below.

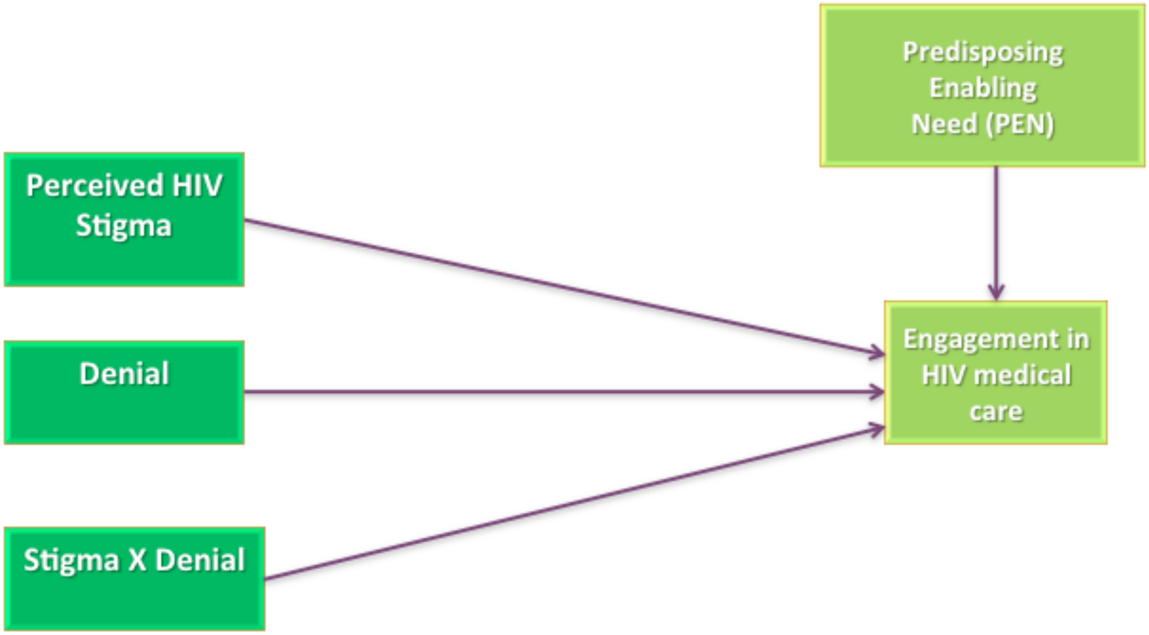


Figure 3-3 Analytical Model

Hypothesis 1 and 2: To determine if differences exist between newly diagnosed and out of care participants' with denial and perceived HIV stigma, t-test were performed for continuous variables and Chi-square analysis for categorical variables.

Hypothesis 3, 4, 5: To determine if a relationship exists between the predisposing, enabling, need variables and engagement in HIV medical care, bivariate correlations were run. Next, logistic regression was performed to determine whether denial and perceived HIV stigma were independent predictors of engagement in HIV medical care. In the multivariate logistic regression analysis variables that were associated with the outcome variable were included as covariates in addition to the psychosocial variables. Finally, hierarchical logistic regression analysis using stepwise and enter method were conducted. All predisposing and enabling variables that were associated with the dependent variable were included in the model in addition to the psychosocial variables.

Hypothesis 6: Hierarchical logistic regression model using stepwise and enter method were used to examine whether denial and perceived HIV stigma had a synergistic relationship when predicting engagement in HIV medical care. All predisposing and enabling factors associated with the dependent variable were added to the model first, next, the psychosocial independent variables, denial and perceived HIV stigma were added to the model. Last of all, the interaction term of denial and perceived HIV stigma was added to the model, to test the synergistic effects of the two variables over and above their individual contribution on engagement in HIV medical care.

Methodological Assumptions

The strength of the study is that it used an existing infrastructure (The Positive Pathways Program), with multiple study sites that had the ability to reach the target population. The scales that were used in this study have been tested and found to be valid and had adequate internal reliabilities greater than .70. According to Nunnally and Bernstein (1994), Cronbach's alpha of .70 indicates good internal consistency. Also, the CHWs conducted one-one interviews with participants that included reading of assessments to participants; as a result this helped overcome literacy issues participants may have encountered with a self- administered survey. Furthermore, the CHWs have met educational requirements for reading as part of their CHW training program from the University of the District of Columbia.

Human Subjects

This study was approved by the District of Columbia Department of Health (Appendix A) and the University of Maryland at College Park Institutional Review Boards Appendix (B).

Chapter 4: Results

Overview of the Chapter

This chapter presents the results of data analyses conducted examining denial and perceived HIV stigma as barriers to engagement in HIV medical care for PLWHA. This chapter includes the study design flow chart showing sample recruitment and participation, an analysis of excluded cases, and the results related to each study hypothesis. The results are based on the following analysis. First, the rates were calculated on both the total and disclosed sample. Second, t-test and chi- analyses were conducted to determine if newly diagnosed and out of care persons differ by their rates on the psychosocial variables. Next, logistic regression analyses were conducted to examine the impact of denial and perceived HIV stigma on engagement in HIV medical care. Finally, hierarchical logistic regressions were conducted to determine the impact of the psychosocial, predisposing, enabling and need variables on the outcome variable.

The results are presented for the total and disclosed sample. The reason for the separation was that almost half the participants reported that they had not disclosed their HIV positive status to someone. The first analysis of the chapter is with the total sample (N=262). These analyses all exclude perceived HIV stigma but include the denial and disclosure variables to answer the research questions and hypotheses related to denial in the total sample. Next, the second set of analyses included only the persons who disclosed their HIV status to others (N=120). The disclosed sample analyses were performed with the denial and perceived HIV stigma measures, which allowed for all research questions and hypotheses to be answered in this restricted sample.

Study Design

There were 352 persons eligible, enrolled and completed the baseline assessment. The flow diagram in Figure 4.1 shows how the study sample participated in the study. Participants completed assessments with community health workers at baseline, 45 and 90-day follow-up.

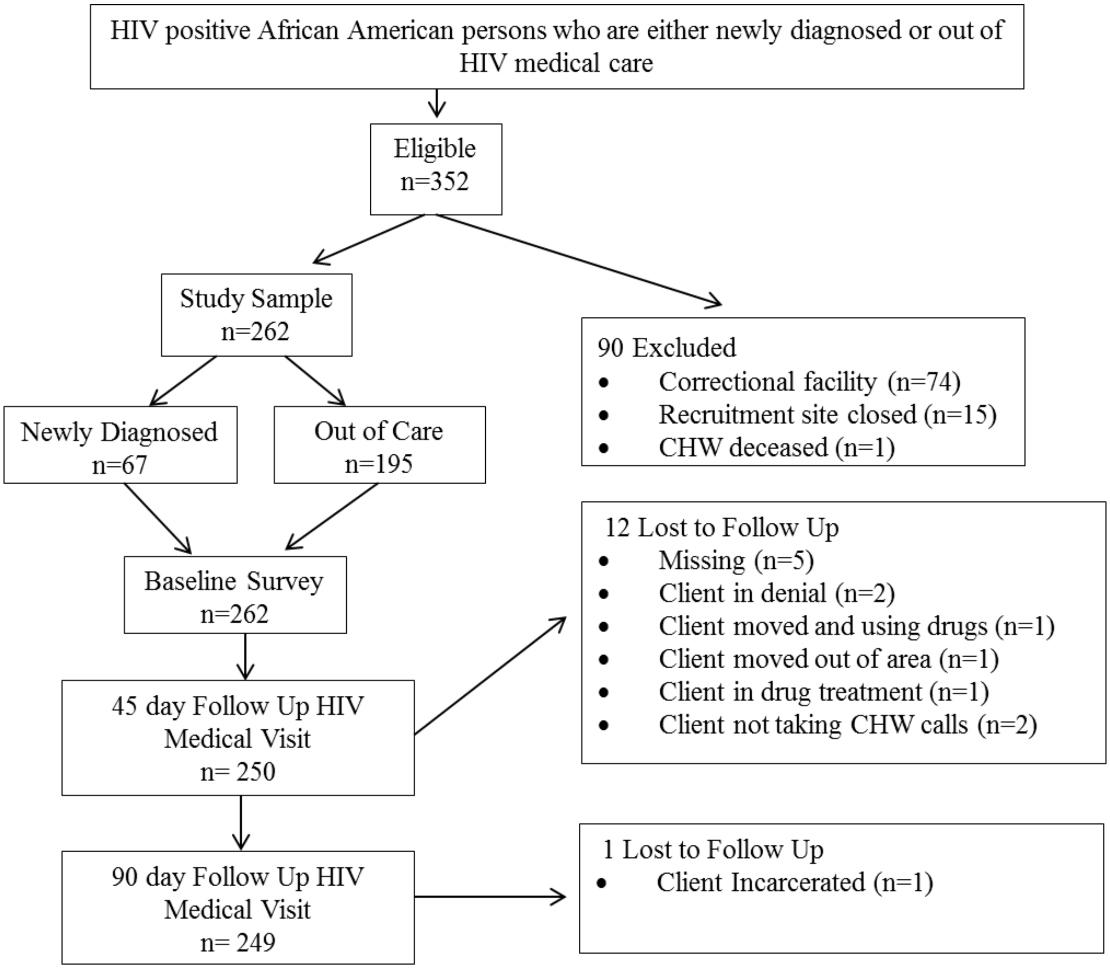


Figure 4-1 Study participant flow diagram of enrollment and engagement in HIV medical care

Excluded cases

Of the 352 persons enrolled, 262 were retained in the final analysis. The other participants who were recruited for the study were excluded for a number of reasons. First, one community health worker passed away and follow-up assessment could not be completed with the clients. Second, a community-based participating site closed down, and finally some participants were recruited from a pre-release correctional facility and many were sent to prison and they would not be followed up about subsequent medical visits in the same manner as the study design required.

Total Sample Analysis (N=262)

This analysis was conducted with the total sample (N=262). Table 4. 1 presents the categorical sociodemographic characteristics of the 262 study participants. Slightly more than half (55%) of the participants were female, 73% were single, and 44% had obtained a high school diploma or GED. Sixty percent reported being unemployed and 84% had an annual income of $15,000 or less. Ninety percent (n=222) of participants indicated that they had health insurance and 79% had a medical home. Almost half (46%) of participants had not disclosed their HIV status to others.

Table 4.1 also compares the characteristics of the sample by client type (newly diagnosed and out of care). There were differences between the groups by disclosure status and engagement in HIV medical care (p<. 05).

Table 4-1 Participant Sociodemographic Characteristics by Client Type (N=262)

Characteristic	**Total[a] (n=262)**	**Newly Diagnosed (n=67)**	**Out of Care (n=195)**	**X^2 (df)**	**p-value**
Gender (n, %)				3.3(1)	0.07
Male	115(44)	36(54)	79(41)		
Female	145(55)	31(46)	114(59)		
Education (n, %)				5.7(2)	0.06
Less than High School	94(37)	16(25)	78(41)		
High School Diploma or GED	115(44)	36(55)	79(41)		
Some College or Technical School/College Degree or Higher	47(18)	13(20)	34(18)		
Employment Status (n, %)				5.1(2)	0.08
Able to Work, employed	42(16)	14(22)	28(15)		
Able to Work, unemployed	155(60)	42(65)	113(59)		
Unable to Work	60(23)	9(14)	51(26)		
Income (n, %)				0.43(1)	0.51
< 15K	217(84)	53(82)	164(85)		
>15 K	41(16)	12(18)	29(15)		
Marital Status (n, %)				0.92(1)	0.34
Single/ Separated/Divorced/Widowed	199(76)	48(72)	151(77)		
Partnered/Married	63(24)	19(28)	44(23)		
Medical Home (n, %)				1.1(1)	0.30
No	79(34)	23(39)	56(32)		
Yes	157(66)	36(61)	121(68)		
Health Insurance (n, %)				0.24(1)	0.63
No	27(10)	6(9)	21(11)		
Yes	222(90)	59(91)	163(89)		
Disclosure (n, %)				13.1(1)	**0.001**
Yes	120(54)	16(31)	104(60)		
No	104(46)	35(69)	69(40)		
Engagement				4.4(1)	**0.03**
Yes	188(72)	55(82)	133(68)		
No	74(28)	12(18)	62(32)		
Engagement – 45 day				6.2(1)	**0.01**
Yes	175(67)	53(79)	122(63)		
No	87(33)	14(21)	73(37)		
Engagement -90 day				11.1(1)	**0.001**
Yes	100(38)	37(55)	63(32)		
No	162(62)	30(45)	132(68)		

Note: [a]The column totals may not sum to total due to missing data

Table 4.2 presents a summary of the continuous variables at baseline. Overall, participants had a mean age of 41years of age (range 18-65, SD= 11.9), on average they reported about two needs and one barrier to engaging in HIV medical care. For clinical markers, participants had a mean CD4 count of 447 cells/mm^3 , and an average HIV viral load of about 20K copies /ml, with about 40% of the sample reporting <200 copies/ml. Examining the psychosocial and structural variables, on average the responses were just below or at the mean on each of the scales. A comparison by client type revealed differences by age (42 vs. 35, p=.00), client needs (p=.02) and client reported barriers (p=.01). Out of care persons were older, and had more needs and barriers to care than newly diagnosed persons.

Table 4-2 Participant Characteristics by Client Type for Continuous Variables (N=262)

Characteristic	**Total (N)**	**Total Mean (SD)**	**Newly Diagnosed (N=67) Mean (SD)**	**Out of Care (N=195) Mean (SD)**	**t (df)**	**p-value**
Age	260	40.32 (11.98)	34.90 (12.18)	42.20 (11.35)	-4.5(259)	**0.00**
CD4 Count	240	446.62 (299.31)	426.25 (243.47)	453.25 (315.70)	-0.07(238)	0.49
HIV Viral Load	220	20303.70 (39749.68)	19057.12 (29424.76)	20670.34 (43377.74)	-.025(218)	0.80
Client Reported Needs	258	2.30 (1.98)	1.80 (1.78)	2.47 (2.02)	-2.4(256)	**0.02**
Client Reported Barriers	262	1.12 (1.53)	0.75 (1.25)	1.25 (1.61)	-2.3(260)	**0.01**
Quality of life	228	2.63 (1.1)	2.8(.86)	2.59 (1.1)	0.93(226)	0.32
Barriers to Care Scale	237	1.82 (0.75)	1.78 (0.76)	1.83 (0.74)	-0.69(235)	0.49

Denial Scale	233	1.58 (.94)	1.63 (.89)	1.57 (0.95)	0.39(231)	0.69

Note: ^{a} The column total may not sum to total due to missing data.

Table 4.3 presents the categorical characteristics of participants by engagement in HIV medical care. Approximately 75 % of the sample was out of HIV medical care at enrollment. Significant differences in engagement in HIV medical care were found by client type (p=.03) and marital status (p=.03). A comparison by client type showed that out of care were less likely to engage in HIV medical care as compared to newly diagnosed and single persons compared to those who were partnered or married.

Table 4-3 Participant Characteristics by Engagement in HIV Medical Care (N=262)

Characteristic	**Total (N=262)^a**	**Not Engaged (N=74)**	**Engaged (N=188)**	**X^2 (df)**	**p-value**
Client Type (n, %)				**4.7(1)**	**0.03**
Newly Diagnosed	67(25)	12(16)	55(29)		
Out of Care	195(75)	62(84)	133(71)		
Gender (n, %)					
Male	114(44)	29(40)	88(45)	0.63(1)	0.43
Female	145(55)	43(60)	102(55)		
Race (n, %)					
African American /Black	262(100)				
Education (n, %)					
Less than High School	93(37)	28(41)	66(34)	1.2(2)	0.55
High School Diploma or GED	115(45)	30(44)	85(46)		
Some College or Technical School/College Degree or Higher	47(18)	10(15)	37(20)		
Employment Status (n, %)					
Able to Work, Employed	41(16)	12(17)	30(15)	0.03(2)	0.87
Able to Work, Unemployed	155(60)	44(62)	111(61)		
Unable to Work	60(23)	15(21)	45(24)		
Income (n, %)				0.24(1)	0.63
< 15K	217(84)	61(86)	156(83)		
>15 K	41(16)	10(14)	31(17)		
Marital Status (n, %)					
Single/Separated/Divorced/ Widowed	199(76)	63(83)	136(69)	**4.8(1)**	**0.03**

Partnered/Married	63(24)	11(17)	52(27)		
Medical Home (n, %)				1.9(1)	0.17
No	79(34)	17(27)	62(37)		
Yes	157(66)	47(73)	110(63)		
Health Insurance (n, %)				1.9(1)	0.17
No	27(11)	4(6)	23(13)		
Yes	222(90)	60(94)	162(87)		
Disclosure (n, %)				1.9(1)	0.16
No	104(46)	32(54)	72(44)		
Yes	120(54)	27(46)	93(56)		

Note: [a]The column totals may not sum to total due to missing data.

Table 4.4 shows the continuous variables by engagement in HIV medical care. None of the continuous variables were associated with engagement in HIV medical care (p>.05). Participants who did not engage in HIV medical care reported higher average CD4 count, denial, and perceived HIV stigma scale scores.

Table 4-4 Participants Characteristics by Engagement in HIV Medical Care for Continuous Variables (N=262)

Characteristic	Total (N)[a]	Total Mean (SD)	Not Engaged (N=74) Mean (SD)	Engaged (N=188) Mean (SD)	t(df)	p-value
Age	261	40.32 (11.98)	40.47 (11.43)	40.26 (12.22)	0.13(259)	0.89
CD4 Count	240	446.62 (299.31)	505.06 (283.54)	424.91 (302.87)	1.85(238)	0.07
HIV Viral Load	220	20303.70 (39749.68)	16601.88 (32586.06)	21660.26 (42081.46)	-0.84(218)	0.40
Client Reported Needs	258	2.30 (1.9)	2.18 (2.03)	2.35 (1.96)	0.65(256)	0.52
Client Reported Barriers	262	1.12 (1.54)	1.32 (1.63)	1.04 (1.49)	1.36(260)	0.19
Barriers to Care	237	1.8	1.78	1.83	-0.47(235)	0.59

Scale		(0.69)	(0.64)	(0.78)		
Quality of Life	228	2.63 (1.1)	2.76 (.94)	2.57 (1.1)	1.21(226)	0.23
Denial Scale	233	1.6 (0.94)	1.68 (0.99)	1.55 (0.92)	0.99(231)	0.32

Note: [a]The column totals may not sum to total due to missing data

Univariate Analysis

Univariate descriptive analyses were performed using rates, means, standard deviations, percentages, and Cronbach's alpha.

Denial in the Total Sample

Rate of Denial in the Total population

The rate of denial in this population was calculated using the four items contained in the COPE-denial subscale. A mean denial scale was created with the 4 items. After the creation of the mean scale the responses were dichotomized with "1" set to "0" and all other scores greater than 1, were set to "1". All scores of "0" represented 'no denial' and any score greater than 1" denoted the 'presence of denial'. Denial was defined as a participant saying yes to at least 1 of the denial items. The total participants who reported no denial were (N=145) and the total that reported some level of denial a score of greater than 1 was (N=88). The total sample was 233 because 29 participants did not answer all the denial questions. To calculate the rate of denial in the population the frequencies were summed to obtain the total numbers of 'yes' responses to each of the items and the total of 'no' responses. The total yes responses were divided by the total (yes responses + no responses). The rate of denial was calculated at 38% in this population. More than one-third of the population had experienced some level of denial in the month before enrollment.

Table 4-5 Rate of Denial in the Total Sample (N=262)

Denial Items	Yes* N (%)
I say to myself this isn't real	67(25)
I refuse to believe that is has happened	55(20)
I pretend that it really hasn't happened	58(22)
I act as though it hasn't even happened	56(21)

Note: *Denial=rarely, sometimes, and often.

Differences in Denial by Client Type

To determine whether there were differences in the level of denial by client type, t-test analysis was conducted. The newly diagnosed persons reported higher levels of denial than out of care persons (1.63 vs.1.57) respectively. This difference was not statistically significant t (233) =0.39, p=0.69. See Table 4.4.

Descriptive Statistics and Cronbach's alpha for Denial Scale (N=262)

Descriptive statistics and Cronbach's alpha were calculated for the denial mean scale for on the total sample. The mean for this scale was 1.58 (SD=0.93). The scale had good internal consistency with a Cronbach's alpha of 0.93.

Table 4-6 Descriptive statistics and Cronbach's alpha for the Denial Scale (N=262)

Scale	N	M (SD)	Observed Range	Theoretical Range	Cronbach's Alpha
Denial Mean Scale	233	1.58(.93)	1-4	1-4	0.93

Bivariate Analysis

Correlations for Total Sample (N=262)

Bivariate correlations were conducted to determine the relationship between denial and the study variables in the total sample (Table 4.7). Denial was negatively correlated with both medical home and disclosure ($p<0.01$), but positively correlated with BAC ($p<0.01$).

Table 4-7 Pearson Correlations between Denial and Study Variables (N=262)

Variable	**Denial**
1.Client Type	-0.03
2.Age	0.01
3.Female Gender	0.12
4. Health Insurance	0.05
5. Medical Home	**-0.22****
6. CD4 Count	-0.06
7. HIV Viral Load	0.10
8. Engagement	-0.07
9.Income	-0.09
10.Client Needs	-0.09
11.Client Barriers	0.06
12. Able to Work, Employed vs. Unable to work	-0.07
13.Able to Work, Unemployed vs. Unable to Work	0.09
14. Single/Separated/Divorced /Widowed vs. Partnered Married	0.09
15. Some College/Tech School /College Education or Higher vs. less than High School	0.01
16.High school/GED vs. less than High School	0.003
17 Quality of Life	-0.02
18.Disclosure	**-0.23****
19.Denial Mean Scale	1
20.BAC Mean Scale	**0.25****

Regression Analysis

Logistic Regression Analysis for Denial

To determine the effect of denial on engagement in HIV medical care, unadjusted and adjusted logistic regression models were run, regressing engagement in HIV medical care on denial. For the adjusted logistic regression analysis two selection methods were used, enter and forward selection. These two methods were chosen because of the possibility of the large number of variables that could have been included in the model. Specifically the concern was that the regression model may not be stable and a reliable measure of engagement in HIV medical care if a significant number of predictors were included in the model. Since the different approaches yielded similar results, there was more confidence in the stability and reliability of the model findings.

Results from the bivariate analysis with the total sample were used to determine which variables to include in the adjusted logistic regression models. Client type, marital status, medical home and disclosure status were found to be associated with engagement in HIV medical care and denial were included in the adjusted logistic regression models.

The adjusted logistic regression analysis using the enter method contained all variables found associated with the dependent variable and the denial mean scale. The second method was the forward method. The adjusted logistic regression analysis was conducted using forward stepwise method. Client type, marital status, medical home and disclosure and denial mean scale were entered into the model and maintained in the model only if they were significantly associated with engagement in HIV medical care. The criterion for a variable to be entered into the model was $p< .05$ and for a variable to be removed was $p>.10$.

Unadjusted Logistic Model

Unadjusted Logistic regression analysis was conducted to assess the direct association of denial and engagement in HIV medical care. Engagement in HIV medical care was regressed on the denial mean scale (Table 4.8). Denial was not a significant predictor of engagement in HIV medical care for this population (OR=0.86; 95% CI [0.64, 1.2]; p=. 32).

Table 4-8 Unadjusted Logistic regression analysis for Denial on Engagement in HIV medical care (N=262)

Variable	B	S.E.	Wald	df	p-value	O.R.	95% CI
Denial Mean Scale	-0.15	0.15	0.99	1	0.32	0.86	0.64- 1.2
Constant	1.2	0.29	17.7	1	0.00	3.40	

Adjusted Logistic Regression

In the adjusted logistic regression model, engagement in HIV medical care was regressed on denial controlling for the covariates, client type, medical home, marital status and disclosure status.

Forward Stepwise Model

Engagement in HIV medical care was regressed on denial controlling for client type, medical home, marital, disclosure status). Disclosure of HIV status to others (OR= 2.2; 95%CI [1.2, 4.3]; p=. 01) and marital status (partnered/married) (OR=2.5; 95%CI [1.0-6.2]; p=.04) were significant predictors of engagement in HIV medical care.

Table 4-9 Adjusted Logistic regression analysis (Forward stepwise) for Denial and Engagement in HIV medical care (N=262)

Variables	B	S.E.	Wald	df	Sig.	O.R.	95% CI
Disclosure	0.81	0.33	5.9	1	0.01	2.20	1.2- 4.3

Partnered/Married	0.93	0.46	4.2	1	0.04	2.50	1.0-6.2
Constant	-0.59	0.58	1.1	1	0.30	0.55	

Enter Model

Engagement in HIV medical care was regressed on denial, controlling for client type, medical home, single vs partnered, and disclosure. Disclosure of HIV status to others was a significant predictor of engagement in HIV medical care (OR= 2.6; 95% CI [1.3, 5.1]; p=. 008). Denial was not a significant predictor of engagement in HIV medical care (p=. 27).

Table 4-10 Adjusted Logistic regression analysis (Enter Model) for Denial and Engagement in HIV medical care (N=262)

Variables	B	S.E.	Wald	df	p-value	O.R.	95% CI
Client Type	-0.81	0.47	3.0	1	0.08	0.44	0.18-1.1
Medical Home	-0.67	0.39	2.8	1	0.09	0.52	0.24-1.1
Partnered/Married	0.79	0.47	2.8	1	0.09	2.21	0.88-5.5
Disclosure	0.94	0.35	7.1	1	**.008**	2.55	1.3-5.1
Denial Mean Scale	-0.20	0.18	1.2	1	0.27	0.82	0.57-1.1
Constant	1.73	0.64	7.3	1	0.01	5.62	

Summary of Logistic Regression for Denial

Examining the direct effect of denial on engagement in HIV medical care in the total sample revealed that denial was not a significant predictor of engagement in HIV medical care for this study population. Disclosure of HIV status to others was a significant predictor of engagement in HIV medical care. None of the predisposing, enabling, and need variables were predictors of engagement in HIV medical care in the total sample.

Disclosed Sample Analysis (N=120)

This second analysis was completed with the participants who completed the perceived HIV stigma measure, and have disclosed their HIV status to others. There were 120 participants that disclosed their HIV status to others and were included in the analyses below.

Table 4.11 presents the categorical variables for the 120 participants who had disclosed their HIV status by client type. Similar to the total sample, persons who disclosed HIV status were 55% female, 71% single, and 51% had obtained a high school diploma or GED. Fifty seven percent (n=67) reported being unemployed and 84% had an annual income of $15,000 or less. Ninety percent of participants indicated that they had health insurance and 79% had a medical home. Table 4.11 also compares the characteristics of newly diagnosed to out of care persons. There were differences in client type by gender (p=. 01).

Table 4-11 Participant Characteristics of persons who Disclosed HIV status by Client type (N=120)

Characteristic	Total (n=120)[a]	Newly Diagnosed (n=16)	Out of Care (n=104)	X^2 (df)	p-value
Gender (n, %)				**6.2(1)**	**0.01**
Male	55(46)	12(74)	43(42)		
Female	64(54)	4(25)	60(58)		
Education (n, %)				5.1(2)	0.08
Less than High School	35(30)	1(6)	35(34)		
High School Diploma or GED	61(51)	11(69)	50(49)		
Some College or Tech School/College Degree or Higher	22(19)	4(25)	18(19)		
Employment Status (n, %)				2.6(2)	0.27
Able to Work, Employed	20(17)	2(13)	29(28)		
Able to Work,	67(57)	12(75)	55(54)		

Unemployed					
Unable to Work	31(26)	2(13)	29(28)		
Income (n, %)				2.4(1)	0.12
< 15K	95(81)	10(67)	85(83)		
>15 K	22(19)	5(33)	17(17)		
Marital Status (n, %)				0.0(1)	1.00
Single/Separated/Divorced/ Widowed	90(75)	12(75)	78(75)		
Partnered/Married	30(25)	4(25)	26(25)		
Medical Home (n, %)				2.0(1)	0.16
No	32(29)	6(46)	26(27)		
Yes	77(71)	7(54)	70(73)		
Health Insurance (n, %)				0.09(1)	0.76
No	10(9)	1(7)	9(9)		
Yes	104(91)	14(93)	90(91)		
Disclosure (n, %)					
Yes	120(100)	16(13)	104(87)		
Engagement				0.09(1)	0.76
Yes	94(78)	13(81)	81(78)		
No	26(22)	3(19)	23(22)		
Engagement – 45 day				0.48(1)	0.49
Yes	89(74)	13(81)	76(73)		
No	31(26)	3(19)	28(27)		
Engagement -90 day					
Yes	48(40)	9(56)	39(37)	2.0(1)	0.15
No	72(60)	7(44)	65(63)		

Note: [a] The column totals may not sum to total due to missing data

Table 4.12 provides a summary for the continuous variables by client type in the disclosed HIV status sample. Overall, participants mean age was 40 years of age (range 18-65, SD= 11.9), on average they reported about two needs and one barrier to engaging in HIV medical care. For clinical markers participants had a mean CD4 count of 496 cells/mm^3 , and an average HIV viral load of about 20K copies /ml, with about 40% of the sample reporting <200 copies/ml. Examining the psychosocial and structural variables on average the responses were just below or at the mean for each of the scales. A comparison by client type revealed differences in age (p=. 02) and barriers to care scale (p=. 05).

Table 4-12 Continuous Participant characteristics of persons who Disclosed HIV status by Client type (N=120)

Characteristic	Total (N) [a]	Total Mean (SD)	Newly Diagnosed (N=17) Mean (SD)	Out of Care (N=103) Mean (SD)	t(df)	p-value
Age	119	40.48 (12.62)	33.75 (13.96)	41.52 (12.14)	-2.3(117)	**.021**
CD4 Count	111	496.14 (324.19)	484.47 (215.05)	485.19 (326.06)	-.008(109)	0.99
HIV Viral Load	98	22547 (44446.84)	29518.40 (31406.77)	21755 (45763.88)	0.52(96)	0.60
Client Reported Needs	117	2.55 (1.99)	2.60 (2.09)	2.54 (1.99)	0.11(115)	0.91
Client Reported Barriers	120	1.04 (1.42)	0.69 (1.49)	1.10 (1.41)	-1.1(118)	0.29
Quality of Life	108	2.63 (1.2)	2.8 (0.73)	2.6 (1.2)	0.46(106)	0.65
Barriers to Care Scale	118	1.69 (0.65)	1.39 (0.42)	1.75 (0.67)	-2.0(116)	**0.05**
Denial Scale	118	1.36 (0.72)	1.14 (0.29)	1.39 (0.76)	-1.3(116)	0.19
Perceived HIV Stigma Scale	120	1.71 (0.79)	1.46 (0.69)	1.76 (0.79)	-1.4(118)	0.17

Note: [a]The column totals may not sum to total due to missing data

Table 4.13 presents categorical characteristics by disclosure status for the total sample. Seventy-seven percent of the sample was out of HIV medical care. More than half of the study participants (55%) were female, 72% single, and 47% had obtained a high school diploma or GED, and only 13% reported being employed. Table 4.13 also examines differences by disclosure status; there were significant differences by client type and engagement in HIV medical care ($p < .05$). Persons who had not disclosed their HIV status and out of care persons were less likely to engage in HIV medical care as compared to persons who had disclosed their HIV status and newly diagnosed persons.

Table 4-13 Participant characteristics by Disclosure status (N=224)

Characteristic	Total[a] (n=224)	Non-Disclosed (n=104)	Disclosed (n=120)	X^2 (df)	p-value
Client Type (n, %)				13.1(1)	**0.00**
Newly Diagnosed	51(23)	35(34)	16(13)		
Out of Care	173(77)	69(66)	104(87)		
Gender (n, %)				0.05(1)	0.82
Male	101(46)	46(45)	55(46)		
Female	121(55)	57(55)	64(54)		
Education (n, %)				5.6(2)	0.06
Less than High School	82(37)	46(45)	36(30)		
High School Diploma or GED	103(47)	42(42)	61(51)		
Some College/ Technical School/College Degree or Higher	35(16)	13(13)	22(19)		
Employment Status (n, %)				5.3(2)	0.07
Able to Work, Employed	30(13)	10(10)	20(17)		
Able to Work, Unemployed	140(64)	73(72)	67(57)		
Unable to Work	50(23)	19(19)	31(26)		
Income (n, %)				1.9(1)	0.16
< 15K	187(85)	92(89)	95(81)		
>15 K	33(15)	11(11)	22(19)		
Marital Status (n, %)				0.28(1)	0.87
Single/Separated/Divorced/Widowed	169(75)	79(76)	90(75)		
Partnered/Married	55(25)	25(24)	30(25)		
Medical Home (n, %)				0.51(1)	0.48
No	63(32)	32(34)	32(29)		
Yes	137(68)	60(66)	77(71)		
Health Insurance n, %)				0.36(1)	0.56
No	21(10)	11(11)	10(9)		
Yes	191(90)	87(89)	104(91)		
Engagement in HIV Medical Care (n, %)					
No	59(26)	32(31)	27(23)	1.9(1)	0.16
Yes	165(74)	72(69)	93(77)		
Engagement				4.04(1)	**0.04**
Yes	163(73)	69(66)	94(78)		

No	61(27)	35(34)	26(22)		
Engagement – 45 day				3.5(1)	0.60
Yes	154(69)	65(63)	89(74)		
No	70(31)	39(37)	31(26)		
Engagement -90 day				1.3(1)	0.26
Yes	82(37)	34(33)	48(40)		
No	142(63)	70(67)	72(60)		

Note: ^{a} The columns may not sum to total due to missing data

Table 4.14 examines continuous variables by disclosure status in the total sample. Significant differences were found for CD4 count and denial. Disclosed persons had higher CD4 count, than non-disclosed persons (p=. 03). Disclosed persons had lower mean denial scale scores compared to non-disclosed persons (p=. 001).

Table 4-14 Participant characteristics by Disclosure status for continuous variables (N=224)

Characteristic	Total (N)	Total (Mean, SD)	Non-Disclosed (N=104) (Mean, SD)	Disclosed (N=120) (Mean, SD)	t(df)	p-value
Age	223	40.32 (11.98)	41.09 (10.85)	40.69 (12.87)	0.33(221)	0.74
CD4 Count	207	446.62 (299.31)	404.96 (280.15)	496.14 (324.19)	-2.15(205)	**0.03**
HIV Viral Load	190	203037 (39749)	20397.30 (39353.41)	22547 (44446.84)	-0.35(188)	0.72
Client Reported Needs	221	2.3 (1.9)	2.21 (2.02)	2.55 (1.99)	-1.24(219)	0.22
Client Reported Barriers	224	1.1 (1.5)	1.33 (1.73)	1.04 (1.42)	1.35(222)	0.18
Quality of Life	206	2.63 (1.1)	2.59 (0.97)	2.64 (1.9)	-0.29(204)	0.77
Barriers to Care Scale	219	1.80 (0.70)	1.91 (0.71)	1.68 (0.72)	1.73(217)	0.09
Denial Scale	217	1.6 (0.94)	1.77 (1.07)	1.36 (0.71)	3.44(215)	**0.001**

Note: ^{a} The column total may not sum to total due to missing data.

Table 4.15 presents the categorical variables for persons who disclosed their HIV status by engagement in HIV medical care. There were significant gender differences between engaged and not engaged persons in HIV medical care (p=. 03). Women were less likely to be engaged in HIV medical care than men.

Table 4-15 Participant Characteristics for persons who disclosed HIV status by Engagement in HIV medical care (N=120)

Characteristic	Total (N=120) [a]	Not Engaged (N=26)	Engaged (N=94)	X^2 (df)	p-value
Client Type (n, %)				0.09(1)	0.76
Newly Diagnosed	26(22)	3(12)	13(14)		
Out of Care	94(78)	23(88)	81(86)		
Gender (n, %)					
Male	55(46)	7(27)	48(52)	4.9(1)	**0.03**
Female	64(54)	18(73)	45(48)		
Race (n, %)					
African American	120(100)				
Education (n, %)				5.6(2)	0.06
Less than High School	36(30)	11(44)	25(27)		
High School Diploma or GED	61(51)	13(52)	48(51)		
Some College or Technical School/College Degree or Higher	22(19)	1(4)	21(22)		
Employment Status (n, %)				3.6(2)	0.16
Able to Work, Employed	20(17)	3(12)	17(19)		
Able to Work, Unemployed	67(57)	19(73)	48(52)		
Unable to Work	31(26)	4(14)	25(29)		
Income (n, %)				2.4(1)	0.12
< 15K	95(81)	23(92)	72(78)		
>15 K	22(19)	2(8)	20(22)		
Marital Status (n, %)				0.59(1)	0.44
Single / Separated/Divorced/ Widowed	90(75)	21(81)	69(73)		
Partnered/Married	30(25)	5(19)	25(27)		
Medical Home (n, %)				0.82(1)	0.37
No	32(29)	5(22)	27(31)		
Yes	77(71)	18(78)	59(69)		
Health Insurance (n, %)				0.61(1)	0.44
No	22(19)	1(5)	9(10)		
Yes	92(81)	21(95)	83(90)		

Note: [a]The column total may not sum to total due to missing data.

Table 4.16 illustrates the differences in engagement in HIV medical care for the disclosed sample on the continuous variables. Perceived HIV stigma mean scores were higher for non-engaged persons compared to persons engaged in HIV medical care (p=. 05).

Table 4-16 Participant Characteristics for persons who disclosed HIV status by Engagement in HIV medical care for continuous variables (N=120)

Characteristic	Total (N) [a]	Total (N=120) Mean (SD)	Not Engaged (N=26) Mean (SD)	Engaged (N=94) Mean (SD)	t(df)	p-value
Age	119	40.48 (12.62)	41.19 (12.24)	40.28 (12.78)	0.33(117)	0.75
CD4 Count	110	496.14 (324.19)	493.87 (311.43)	496.74 (329.24)	-0.04(108)	0.97
HIV Viral Load	98	22547.38 (44446.84)	15859.55 (28466.99)	24262.21 (47687.38)	-0.75(96)	0.45
Client Reported Needs	117	2.55 (1.99)	2.54 (2.16)	2.55 (1.96)	-0.03(115)	0.08
Client Reported Barriers	120	1.04 (1.42)	1.23 (1.56)	0.99 (1.39)	0.77(118)	0.44
Quality of Life	108	2.63 (1.2)	2.83 (1.0)	2.57 (1.2)	0.97(106)	0.33
Barriers to care Scale	118	1.69 (0.65)	1.77 (0.64)	1.68 (0.65)	0.60(116)	0.55
Denial Scale	118	1.36 (0.71)	1.50 (0.72)	1.32 (0.71)	1.17(116)	0.25
Perceived HIV Stigma	120	1.71 (0.79)	1.97 (0.82)	1.65 (0.76)	1.95(118)	**0.05**

[a] The column total may not sum to total due to missing data.

Denial in Disclosed Sample (N=120)

Rate of Denial

Table 4.17 presents the rate of denial in the disclosed sample which was calculated using the four items contained in the COPE-denial subscale. A mean denial scale was created with the 4 items. After the creation of the mean denial scale the responses were dichotomized with “1” set to “0” and all other scores greater than 1, were set to “1”. All scores of “0” represented ‘no denial’ and any score greater than 1” denoted the ‘presence of denial’. Denial was defined as a participant saying yes to at least 1 of the denial items. The total responses reported for no denial was (N=81) and the total that reported some level of denial was (N=37). The total sample was 118. To calculate the rate of denial in the population the frequencies were summed to obtain the total numbers of ‘yes’ responses to each of the items along the scale and the total of ‘no’ responses. The total yes responses were divided by the total sample (yes responses + no responses) to obtain the total rate of denial in the population. The rate of denial in the disclosed sample was calculated at 31%. Almost one-third of the disclosed population had experienced some level of denial in the month before enrollment.

Table 4-17 Rate of Denial in persons who disclosed HIV status (N=120)

Denial Items	Yes* N (%)
I say to myself this isn't real	24(21)
I refuse to believe that is has happened	16(13)
I pretend that it really hasn't happened	20(16)
I act as though it hasn't even happened	20(17)

Note: *Denial=rarely, sometimes, and often.

Differences in Denial by Client Type (N=120)

To examine the differences in the level of denial by client type for persons who disclosed HIV status to others. A t-test was conducted. The out of care persons reported higher levels of denial than newly diagnosed persons (1.39 vs.1.14) respectively. This difference was not significant (t (116) =-1.3, p=. 19). Results are presented in Table 4.12.

Descriptive Statistics and Cronbach's alpha for Denial Scale (N=120)

Descriptive statistics and Cronbach's alpha were calculated for the denial scale score on the disclosed sample. This scale was created by taking the mean of the 4 items and creating a total scale score that was used in all subsequent analyses. The mean for this scale was 1.36 (SD=0.71). The scale had good internal consistency with a Cronbach's alpha of 0.88.

Table 4-18 Descriptive statistics and Cronbach's alpha for Denial scale of persons who Disclosed HIV status (N=120)

Scale	N	M (SD)	Observed Range	Theoretical Range	Cronbach's Alpha
Denial Mean Scale	118	1.36(0.71)	1-4	1-4	0.88

Pearson's correlations for Disclosed Sample (N=120)

Pearson's correlations were conducted with the disclosed sample (N=120) to determine the relationship between denial, perceived HIV stigma, and all other study variables (Table 4.21). Denial was positively correlated with gender, perceived HIV stigma mean scale and BAC mean scale (p<. 05). The variables positively correlated with the perceived HIV stigma mean scale were gender, denial mean scale, client reported barriers, and barriers to care mean scale (p<. 01). The variables that were negatively correlated with perceived HIV stigma were medical home and employment status(able to work, employed) (p<. 05).

Table 4-19 Pearson's Correlation analysis between denial and perceived HIV stigma and study variables for persons who disclosed HIV status (N=120)

Variables	Denial	Perceived HIV stigma
1.Client Type	.12	.13
2.Age	.11	.14
3. Female Gender	**.33****	**.29****
4. Health Insurance	-.01	.07
5. Medical Home	-.07	**-.23***
6. CD4 Count	-.008	-.07
7. HIV Viral Load	.13	.01
8. Engagement	-.11	-.18
9.Income	-.12	-.12
10.Client Needs	.14	.16
11.Client Barriers	.14	**.22***
12. Able to Work, Employed vs. Unable to Work	-.11	**-.22***
13. Able to Work, Unemployed vs. Unable to Work	.09	.11
14. Single Separated/Divorced /Widowed vs. Partnered /Married	-.08	.09
15. Some College/Tech School/College Education or Higher vs. less than High School	-.04	.04
16.High school/GED vs. less than High School	.06	-.01
17. Quality of Life	-.07	-.17
18.Denial Mean Scale	1	**.49****
19. Perceived HIV Stigma Mean Scale	**.49****	1
20.BAC Mean Scale	**.34****	**.58****

Perceived HIV Stigma in Disclosed Sample (N=120)

Rate of Perceived HIV Stigma Disclosed sample (N=120)

The rate of perceived HIV stigma in the disclosed sample was calculated using the 18 items contained in the Berger's HIV Stigma scale-perceived stigma subscale. A mean perceived HIV stigma scale was created with the 18 items. After the creation of the scale the responses were dichotomized with "1" set to "0" and all other scores greater than 1, were set to "1". All scores of 0 represented 'no perceived HIV stigma' and any score 1 or greater denoted the 'presence of perceived HIV stigma'. The total responses for no perceived HIV stigma was (N=49) and the total participants that reported some level of perceived HIV stigma was (N=71). The total sample size was 120. Perceived HIV stigma was defined as a participant saying yes to at least 1 of the perceived HIV stigma items. To calculate the rate of perceived HIV stigma in the population, the frequencies were summed to obtain the total numbers of 'yes' responses to each of the items along the scale and the total of 'no' responses. The total yes responses were divided by the total (yes responses + no responses) to obtain the total rate of barriers in the population. The rate of perceived HIV stigma reported was calculated at 59% in this population. More than half of the disclosed sample had perceived a level of HIV stigma from others at enrollment.

Table 4-20 Rate of Perceived HIV stigma in persons who disclosed HIV status (N=120)

Perceived HIV Stigma Items	**Yes* N (%)**
I have lost friends by telling them I have HIV	30(26)
I have been hurt by how people reacted to learning I have HIV	36(30)
People avoid touching me if they know I have HIV	12(10)
I stopped socializing with some due to their reactions	32(27)
People I care about stopped calling after learning I have HIV	16(13)
People seem afraid of me because I have HIV	17(15)
Some people who know my HIV status have grown more distant	23(20)
People have physically backed away from me	25(20)
People who know my HIV status tend to ignore my good points	21(18)
Some People don't want me around children once they know my HIV status	15(12)

I feel set apart, isolated from the rest of the world	31(26)
I regret having told people that I have HIV	30(24)
Some people feel they will be rejected because of my HIV status	24(20)
Some people act as though it's my fault I have HIV	20(17)
As a rule, telling others about my HIV Status has been a mistake	23(19)
Most people with HIV are rejected when others learn of their HIV status	33(27)
People have told me that getting HIV is what I deserve for how I lived my life	15(13)
When people learn you have HIV they look for flaws in your character	20(16)

Note: *Perceived HIV stigma= agree and strongly agree.

Differences in Perceived HIV Stigma by client type (N=120)

To determine whether there were differences in the level of perceived HIV stigma by client type, t-test analysis was conducted. The out of care persons reported higher levels of perceived HIV stigma than newly diagnosed persons (1.76 vs.1.46) respectively. This difference was not statistically significant t (116) =-1.3, p=0.19. Results are presented in Table 4.12.

Perceived HIV stigma scale characteristics and Cronbach's alpha (N=120)

Table 4.21 presents the descriptive statistics and Cronbach's analysis for the perceived HIV stigma measure for the disclosed sample. The perceived HIV stigma scale score was created by averaging the individual response items. The average score on the perceived HIV stigma mean scale was 1.71(SD=. 76). The perceived HIV stigma mean scale scores ranged from 1 to 4. Cronbach's alpha was calculated to confirm the internal reliability for the scale in this population, which was 0.97.

Table 4-21 Descriptive statistics and Cronbach's alpha for perceived HIV stigma scale of persons who disclosed HIV status (N=120)

Scale	N	M (SD)	Observed Range	Theoretical Range	Cronbach's Alpha
Perceived HIV Stigma Scale	120	1.71(0.76)	1-4	1-4	0.97

Logistic Regression for Perceived HIV Stigma (N=120)

Unadjusted Model

Unadjusted logistic regression analysis was conducted for the disclosed sample, regressing engagement in HIV medical care on the perceived HIV stigma mean scale (Table 4.22). Perceived HIV stigma was not a significant predictor of engagement in HIV medical care for this population, (OR=0.66; 95 % CI [0.40-1.01]; p=. 10).

Table 4-22 Unadjusted Logistic regression analysis of perceived HIV stigma on engagement in HIV medical care for persons who disclosed HIV status (N=120)

Variables	B	S.E.	Wald	df	p-value	O.R.	95% CI
Perceived HIV Stigma Mean Scale	-0.41	0.25	2.71	1	0.10	0.66	0.40-1.01
Constant	2.17	0.52	15.5	1	0.00	8.79	

Summary of perceived HIV stigma in disclosed sample

Perceived HIV stigma was not a significant predictor of engagement in HIV medical care. Next, the final models are presented using hierarchical logistic regression with the disclosed sample examining whether denial was the most significant predictor of engagement in HIV medical care over all other variables. In addition, the interaction analysis was conducted to examine whether denial and perceived HIV stigma act synergistically to predict engagement in HIV medical care.

Hierarchical Logistic Regression Models (N=120)

Hierarchical logistic regression models were conducted to examine how each set of predisposing, enabling, need and psychosocial variables independently predicted engagement in HIV medical care. The disclosed sample was used in these analyses as all study research questions and hypotheses could be addressed. Predisposing, enabling and need variables significantly associated with engagement in HIV medical care from the bivariate analysis were included in the model. Gender, employment status and educational level were included in the models.

Final Hierarchical Logistic Regression Models, Disclosed Sample (N=120)

Forward Stepwise

Hierarchical logistic regression was conducted using forward stepwise method on each block with only the variables significantly correlated with engagement in HIV medical care, to determine the effect of denial on engagement in HIV medical care in the disclosed sample. The variables were entered into each block and maintained in the model only if they were significantly associated with engagement in HIV medical care. The criterion for a variable to be entered into the model at each step was $p <. 05$ and for a variable to be removed was $p >.10$. In block one, the predisposing variables (client type, gender and education) were added. In block two, the enabling variable (employment status); block three, perceived HIV stigma mean scale and the final block, denial mean scale was added to the model. The predisposing variables, gender and educational level were significant predictors of engagement in HIV medical care ($p <. 05$). Women were less likely to engage in HIV medical care than men (OR=0.29; 95% CI [0.11, 0.79]; $p <. 05$). Participants who had some college education or higher were more likely to have engaged in HIV medical care compared to persons with less high school education (OR=8.3; 95% CI [1.0,67.1]; p= 05). The enabling variable, employment status was a significant predictor of engagement in HIV medical care. Participants who were able to work but unemployed were less likely to have engaged in HIV medical care compared to persons who were unable to work (OR=.34; 95% CI [.12-.93, 67.1]; p= 04). Denial was not a significant predictor of engagement in HIV medical care.

Table 4-23 Hierarchical Logistic Regression analysis (Stepwise Method) for denial on Engagement in HIV medical care (N=120)

Variables	B	S.E.	Wald	df	p-value	O.R.	95 % C.I
Gender	-1.2	0.51	5.8	1	**0.02**	0.29	0.11-0.79
Some College/Tech School/College Education or Higher	2.1	1.1	4.4	1	**0.05**	8.28	1.0-67.1
Able to Work, Unemployed	-1.1	0.51	4.4	1	**0.04**	0.34	0.12-0.93
Constant	2.4	0.56	19.1	1	0.00	11.48	

Enter Model

Hierarchical logistic regression was conducted using the enter method, to determine the effect of denial on engagement in HIV medical care in the disclosed sample. For the enter method all variables are kept in the model and are not removed at each step. In block one, the predisposing variables (client type, gender and education) were added. In block two, the enabling variable (employment status); block three, perceived HIV stigma mean scale and the final block, denial mean scale was added to the model. The predisposing variables, gender and educational level were significant predictors of engagement in HIV medical care over and above the denial mean scale variable (p<. 05). Women were less likely to engage in HIV medical care than men (OR=0.31; 95% CI [0.10, 0.90]; p<. 05). Participants who had some college education or higher were more likely to have engaged in HIV medical care compared to persons with less high school education, (OR=8.4; 95% CI [1.0,68.9]; p= 05). Denial and perceived HIV stigma and were not found to significant predictors of engagement in HIV medical care among persons who have disclosed their HIV status to others.

Table 4-24 Hierarchical Logistic Regression analysis (Enter Method) of denial on Engagement in HIV medical care (N=120)

Variables	B	S.E.	Wald	df	p-value	O.R.	95 % C.I
Client Type	0.13	0.78	0.27	1	0.87	1.13	0.25-5.2
Gender	-1.2	0.54	4.6	1	**0.03**	0.31	0.10-0.90
Some College/Tech School/College Education or Higher	2.1	1.1	3.9	1	**0.05**	8.41	1.0- 68.9
Able to Work, Unemployed	-0.99	0.53	3.5	1	0.06	0.37	0.13-1.0
Perceived HIV Stigma Mean Scale	-0.43	0.34	1.6	1	0.20	0.65	0.33-1.3
Denial Mean Scale	0.17	0.36	0.22	1	0.64	1.18	0.59-2.4
Constant	2.8	0.96	8.2	1	0.004	15.89	

Interaction models

The following models were conducted to determine if denial and perceived HIV stigma had a synergistic relationship in predicting engagement in HIV medical care. Hierarchical logistic regression analyses were conducted with both the forward stepwise and enter method.

Forward Stepwise Model

Hierarchical logistic regression was conducted using forward stepwise method on each block, with the disclosed sample, to determine the interaction effect of denial and perceived HIV stigma on engagement in HIV medical care (Table 4.25). The variables were entered into each block and maintained in the model only if they were significantly associated with engagement in HIV medical care. The criterion for a variable to be entered into the model at each step was p<.

05 and for a variable to be removed was p>.10. In block one, the predisposing variables (client type, gender and education) were added. In block two, the enabling variable (employment status); block three, perceived HIV stigma mean scale, block four denial mean scale. In the final block, the interaction term for denial mean scale and perceived HIV stigma mean scale were added to the model. The predisposing and enabling variables gender, educational level and employment status were significant predictors of engagement in HIV medical care (p<. 05). The interaction term of denial and perceived HIV stigma was not included in the stepwise model and thus was not a significant predictor of engagement in HIV medical care.

Table 4-25 Hierarchical Logistic Regression analysis (Stepwise Method) of the interaction effect of denial and perceived HIV stigma on Engagement in HIV medical care (N=120)

Variables	**B**	**S.E.**	**Wald**	**df**	**p-value**	**O.R.**	**95 % C.I**
Gender	-1.2	0.51	5.9	1	**0.02**	0.29	0.11-0.79
Some College/Tech School/College Education or Higher	2.1	1.1	3.9	1	**0.05**	8.28	1.0-67.1
Able to Work, Unemployed	-1.1	0.51	4.4	1	**0.04**	0.34	0.12-0.93
Constant	2.4	0.56	19.1	1	.000	11.48	

Enter Model

Table 4.26 summarizes the results of the hierarchical logistic regression with the enter method examining the interaction effect of denial mean scale and perceived HIV stigma mean scale on engagement in HIV medical care. For the enter method all variables are kept in the model and are not removed at each step. In block one, the predisposing variables (client type, gender and education) were added. In block two, the enabling variable (employment status); block three, perceived HIV stigma mean scale, block four denial mean scale. In the final block, the interaction term for denial mean scale and perceived HIV stigma mean scale were added to the model. Similar to the stepwise model, gender and educational level were predictors of engagement in HIV medical care for persons who have disclosed HIV status to others. Denial and perceived HIV stigma were not significant predictors of engagement in HIV medical care. The interaction term also was not associated with engagement in HIV medical care (p=.88).

Table 4-26 Hierarchical Logistic Regression analysis (Enter Method) of the moderation effect of denial and perceived HIV stigma on Engagement in HIV medical care (N=120)

Variables	B	S.E.	Wald	df	p-value	O.R.	95 % C.I
Client Type	0.14	0.78	0.03	1	0.86	1.15	0.25-5.2
Gender	-1.2	0.55	4.5	1	**0.03**	0.31	0.11-0.91
Some College/Tech School/College Education or Higher	2.1	1.1	3.8	1	**0.05**	8.26	0.99-68.5
Able to Work, Unemployed	-0.99	0.53	3.5	1	0.06	0.37	0.13-1.0
Perceived HIV Stigma Mean Scale	-0.54	0.79	0.49	1	0.49	0.58	0.13-2.6
Denial Mean Scale	-0.35	1.3	0.01	1	0.98	0.97	0.07-13.0
Denial *Perceived HIV Stigma Scale	0.08	0.53	0.03	1	0.88	1.09	0.39-3.0
Constant	3.0	1.8	2.8	1	0.09	20.71	

Summary of Findings:

The results for the analyses in this chapter were presented for two samples (total and disclosed). In the total sample, disclosure of HIV status was a significant predictor of engagement in HIV medical care. In the disclosed sample, the two predisposing variables (gender and educational level) and enabling variable (employment status) were significant predictors of engagement in HIV medical care. The results did not support the hypotheses that the psychosocial variables denial and perceived HIV stigma were greater predictors of engagement in HIV medical care than predisposing, enabling and need variables.

Chapter 5: Discussion

This chapter includes a summary of key findings as they relate to each research questions and hypotheses, summary of results, significance, study limitation, recommendations for future research and finally the conclusion about the study.

Overview of the Chapter

The purpose of this study was to examine denial and perceived HIV stigma as barriers to persons living with HIV engaging in HIV medical care. This study builds upon previous research, particularly qualitative research that identified psychosocial variables (denial and perceived HIV stigma) as being among the main barriers to PLWHA engagement in HIV medical care. A few studies have examined denial (Nam et al., 2008) and stigma independently (Sayles, Wong, Kinsler, Martin & Cunningham, 2009; Vanable, Carey, Blair & Littlewood, 2006) as well as together qualitatively (Beer et al., 2009; Konkle-Parker et al., 2008/2011) to determine their effect on the health and treatment adherence outcomes for PLWHA. This study sought to add to the literature by studying these two quantitatively, to assess the degree to which denial and perceived HIV stigma from others both separately and together affect PLWHA's engagement or lack of in HIV medical care. The results of this study are presented for two different samples, the total sample (N=262) and the disclosed sample (N=120). The reason for the separation of the results was because almost half the participants (46%) had not disclosed their HIV status to others causing the analysis to be completed with the two different samples.

Summary of Findings in Total Sample

The total sample includes the analysis for research questions (one, three and five) and hypotheses (one, three and four). The disclosed sample will examine the remaining research questions and hypotheses.

Denial in the Total Sample

Rate of Denial in Total Sample

The overall rate of denial of HIV status in the total population was found to be to 38%. These findings are consistent with previous research by Vosvick and colleagues, who examined denial using the COPE scale in PLWHA, but as it related to their quality of life. They found that 37% of the 142 participants used denial as a coping strategy. They also found that denial was not a significant predictor of quality of life (Vosvick et al, 2003).

The rates of denial in this population varied by disclosure status, where persons who disclosed HIV status reported a lower rate of denial as compared to persons who had not disclosed their HIV status. This was calculated using bivariate analysis and did not account for potential confounders. The rates of denial could possibly differ between the two groups, because persons who disclosed HIV status may have come to terms with their HIV diagnosis, whereas people who not disclosed HIV status may be having a difficult time believing that they are really HIV positive.

Disclosure and non-disclosure of HIV status may be a way for PLWHA to cope with diagnosis. For example, previous research by Hult and colleagues, with newly diagnosed PLWHA in the San Francisco area, examined their disclosure habits, and interviewed participants at 1, 3, and 9 months after diagnosis. They found that people who disclosed their HIV status early after diagnosis did so as a way to cope with diagnosis and gain social support from others. Whereas people who did not disclose HIV status, but kept their HIV status a secret did so because they feared possible stigma they would from others (Hult et al., 2012).

Hypothesis 1 Out of care PLWHA will have higher rates of denial than newly diagnosed PLWHA.

It was hypothesized that out of care persons would report higher rates of denial than newly diagnosed persons. This hypothesis was not supported in the total sample. In the bivariate analysis out of care persons reported lower rates of denial as compared to newly diagnosed persons.

Denial and Engagement in HIV Medical Care

Hypothesis 3 Denial will be an independent predictor of engagement in HIV medical care.

The second hypothesis for denial was that it would be an independent predictor of engagement in HIV medical care. This hypothesis was not supported based on the results from the regression analyses. Denial was not a significant predictor of engagement in HIV medical care for this population. In the total sample, interestingly, disclosure of HIV status emerged as the significant predictor of engagement in HIV medical care. The lack of significance for denial as a predictor may have been absorbed by the disclosure variable.

Previous studies have explored denial of HIV status with people living with HIV/AIDS using the COPE-denial subscale. These studies were different from this dissertation study in that their outcome variables were mainly quality of life (Vosvick et al., 2003; Weaver et al., 2004; Weaver et al., 2005, Kamen et al., 2011) and medication adherence (Vyavaharkar et al., 2007).

Weaver and colleagues highlighted the influence of denial on help seeking behavior*s*. First, they conducted a longitudinal randomized trial with HIV positive women to study the effect of stress and denial on quality of life (QOL). Denial was found to be a significant predictor of QOL over and above demographic characteristics (Weaver et al., 2004). Next, with HIV positive men and women they examined the association of stress and denial on antiretroviral medication adherence. The findings suggested that denial was a predictor for less medication adherence for PLWHA. While previous studies found an association of denial with non-adherence to HIV medication, it cannot be inferred that the participants were also not engaging in HIV medical care. No differences were reported about how denial affects men and women differently (Weaver et al., 2005).

However, one study examined the association of denial and HIV health service utilization for HIV positive women in South African (Luseno et al., 2010). Health care utilization was measured at 3 and 6 months after HIV diagnosis. Denial was reported as a significant barrier for health care utilization for these women. However, these results were not tested with a standardized measure, but inferred because some participants delayed coming to the initial appointment at 3 month but attended the 6-month appointment.

This dissertation study is similar to previous quantitative studies with PLWHA in that denial of HIV status was measured using the COPE-denial-subscale (Vosvick et al., 2003; Weaver et al., 2004; Weaver et al., 2005,). However, the studies differ in that many of the quantitative studies examined psychosocial variables as outcomes and not engagement in HIV medical care. In this dissertation study, the multivariate logistic regression analysis showed that denial of HIV status was not associated with engagement in HIV medical care.

Engagement in HIV Medical Care in Total Sample

In the total sample, 72 %(n=190) of sample were engaged in HIV medical care within 90 days of enrollment. This shows that the majority of the sample attended at least one HIV medical visit. This is lower than the 2015 goals of the National HIV/AIDS strategy which is to have 85% of persons in care within 3 months (NHAS). The findings also show that engagement in care varied by client type. Out of care people were less likely to engage in HIV medical care compared to newly diagnosed persons. These findings points to the need to identify the reasons PLWHA tend to fall out of care. The following section discusses the influence of disclosure on engagement in HIV medical care.

Disclosure and Engagement in HIV Medical Care in the Total Sample

In the current study of African American PLWHA, disclosure was an important factor as almost half of participants had not disclosed their HIV status to others. In the total sample, disclosure of HIV status was associated with engagement in HIV medical care. Persons who disclosed HIV status to others were 2.2 times more likely to engage in HIV medical care compared to those persons who has not disclosed HIV status**.** Overall, a large number of participants did not disclose HIV status to others and this lack of disclosure could be a form of HIV stigma.

Main Findings in the Total Sample (N=262)

One of the main findings of this study was that disclosure is a major issue for this population. This was confirmed by the fact that nearly 50% of the sample had not disclosed their HIV status to others. The results for the total sample revealed that disclosure is a significant predictor of engagement of HIV medical care. A person who disclosed their HIV status to others was more likely to engage in HIV medical care than a person who had not disclosed their HIV status to others. There was no relationship between denial and engagement in HIV medical care in the disclosed sample.

Summary of Findings in Disclosed Sample

The findings in the disclosed sample are presented examining denial and then perceived HIV stigma. All research questions and hypotheses are answered but are not presented in sequential order.

Denial in the Disclosed Sample

Rate of Denial in the Disclosed Sample

The rate of denial in the disclosed sample was 31%. This rate was a little lower than the rate in the total sample.

Hypothesis 1 Out of care PLWHA will have higher rates of denial than newly diagnosed PLWHA–Disclosed Sample.

This hypothesis was not supported for the disclosed sample. The results of the bivariate analysis revealed there were no significant differences between level of denial in out of care and newly diagnosed persons. Although the results do not indicate significant differences between the two populations it does show that both used denial as a way to cope with their HIV diagnosis. At least one-fourth of both out of care and newly diagnosed persons reported using denial at baseline as a way to cope with their HIV status in the previous month.

Denial as a Predictor of Engagement in HIV Medical Care

Hypothesis 4 Denial will be a stronger independent predictor of engagement in HIV medical care than other factors.

The next hypothesis was that denial would be a greater predictor of engagement in HIV medical care than all other psychosocial, predisposing, enabling, need and variables in the model. This hypothesis was tested using the disclosed sample, and perceived HIV stigma was included in the analysis. This hypothesis was also not supported. The results of the hierarchical logistic regression analyses revealed that gender, educational level, and employment status were the only variables associated with engagement in HIV medical care. This finding was unanticipated. Nevertheless, it was not surprising as PLWHA who are typically unengaged in HIV medical care are more likely to be women (Rumptz et al., 2007) and have lower education (Kalichman, Catz & Ramachandran 1999) and are unemployed (Cunningham et al.,2007) . Although the original hypotheses were not confirmed it was important to study the effects of denial on HIV medical care, as no studies have examined how the level of denial in PLWHA influences engagement in HIV medical care.

Perceived HIV stigma in the Disclosed Sample

Rate of perceived HIV stigma in Disclosed Sample

The rate of perceived HIV stigma in the disclosed sample is nearly 60 %. Previous research by Sowell et al., (2007) examined perceptions of HIV stigma of women living in rural Georgia and they reported that 40% of women felt people looked down on them because of their HIV status. Fifty-six percent perceived others were uncomfortable around them because they were HIV positive. The rates of perceived HIV stigma ranged from approximately 40-60 % (Sowell et al., 2007). The sample population included women who resided in rural south. The population was different from the current dissertation study in that it contained all women, but both showed similar rates of perception of HIV stigma.

Another study conducted with young people living with HIV to determine predictors of HIV stigma in the population, revealed that 89% of participants perceived HIV stigma from others in the prior 3 months (Swendeman et al., 2006). This rate is little higher than reported in the current sample. The higher rate of stigma could be attributed to sample consisting of predominately of young MSM with different gender, racial and age variations. In a recent study by Reif et al., (2015) conducted in Washington D.C., with PLWHA at risk of falling out of medical care, they also found slightly higher levels of perceived HIV stigma than participants in the current study. One reason for the differences could be the characteristics of their sample, which was 78% male and 83% African American, compared to the participants in the current study sample were all African American and only 44% male. In addition, Galvan and associates studied HIV stigma and social support in African American PLWHA also using the Berger's HIV stigma scale and they also reported higher level of HIV stigma than the current study (Galvan et al., 2008). The sample likewise differed from the current study in that there were more males in study (70%) and the study was conducted in a different geographic area of the United States. Level of perceived HIV stigma in the current sample may be lower because of the separation of the sample by disclosure status, which reduced the sample size by one-half. If all participants were able to answer the perceived HIV stigma questions, results in this study may have been comparable to other studies. In the previous studies the samples also consisted of more males than females. Additional studies to examine if perceived HIV stigma differs by gender are needed.

Hypothesis 2 Out of care PLWHA will have higher rates of perceived HIV stigma than newly diagnosed PLWHA.

The current study also hypothesized that out of care persons would have higher rates of perceived HIV stigma newly diagnosed persons. The hypothesis was supported in the disclosed sample; in the bivariate analysis out of care persons had a higher rate of perceived HIV stigma as compared to newly diagnosed persons. This difference may be explained by the fact that out of care persons who have disclosed HIV status to others, have had longer time dealing with HIV status and may have perceived or have had negative experiences from others because of their HIV status. Research also indicates that HIV stigma is more often found among people who have disclosed HIV status to others (Vanable et al., 2006).

Perceived HIV Stigma and Engagement in HIV Medical Care in the Disclosed Sample

Hypothesis 5 Perceived HIV stigma will be an independent predictor of HIV care engagement

The next hypothesis was that perceived HIV stigma would be an independent predictor of engagement in HIV medical care. This hypothesis was not supported. This was examined in the disclosed sample only. In the unadjusted logistic regression models, perceived HIV stigma was not a predictor of engagement in HIV medical care for PLWHA who had disclosed their HIV status to others. This finding was surprising since many researchers have reported that HIV stigma is one of the main barriers that keep people out of medical care. Some studies reported that PLWHA who feared or experienced HIV stigma were less likely to take HIV medications, and attend HIV medical appointments for fear of others finding out about their HIV status (Konkle – Parker et al., 2011; McDoom et al., 2014; Rintamaki et al., 2006; Vanable et al., 2006). However, many of these studies used qualitative research methods to examine HIV stigma in their sample.

Although very few studies have examined quantitatively perceived HIV stigma and its association with engagement in HIV medical care. One such study by Wolitski et al. (2008), did examine HIV stigma, but with unstably housed PLWHA, in Washington DC, and its association with engagement in HIV medical care. In this study a modified version of Berger's HIV stigma-perceived HIV stigma subscale was used. They reported that perceived HIV stigma was not associated with of utilization of HIV medical care (Wolitski et al. 2008). In addition, Sayles and colleagues (2009), in their study with PLWHA in Las Angeles, California also reported that HIV stigma was not associated with regular HIV care (Sayles et al., 2009). These results are similar to the current dissertation study in that perceived HIV stigma was not associated with engagement in HIV medical care. This lack of significance in the current study confirms previous findings, but could possibly be attributed to reduced sample size and not enough power to detect a difference because many participants had not disclosed HIV status and less than half the sample could be included in the analysis. These findings underscore the need for additional quantitative research to explain the relationship between perceived HIV stigma and engagement in HIV medical care.

Hypothesis 6 Denial and stigma have a synergistic relationship when predicting engagement in HIV medical care

The final hypothesis was that denial and perceived HIV stigma would have a synergistic relationship when predicting engagement in HIV medical care. This hypothesis was not supported, as both denial and perceived HIV stigma were not associated with engagement in HIV medical care. The results of the hierarchical logistic regression analysis examining the interaction effect of denial on perceived HIV stigma and engagement in HIV showed an insignificant interaction term. This relationship was only examined in the disclosed sample, and this effect may have been difficult to identify because of decreased sample size. In the bivariate analysis, out of care persons did report a greater level of perceived HIV stigma and denial than newly diagnosed persons. Therefore, they may have been using denial of HIV status to cope with HIV stigma that they perceived or have received from others.

Engagement in HIV medical care in the Disclosed Sample

In the disclosed sample, 78 % of participant engaged in HIV medical care within 90 days of enrollment. The findings did not show that engagement in care varied by client type. In out of care and newly diagnosed persons, engagement was reported at similar rates. Low sample sizes were probably a factor as to why these findings are different from what was observed in the total sample. In the total sample, out of care persons were less likely to engage in HIV medical care than newly diagnosed persons.

Disclosure and Engagement in HIV Medical Care in the Disclosed Sample

In the disclosed sample, there was a relationship between perceived HIV stigma and engagement in HIV medical care. The bivariate analysis showed that persons who disclosed their HIV status and were not engaged in HIV medical care reported higher levels of perceived HIV stigma than persons who were engaged in HIV medical care. Among persons who had disclosed their HIV status, engagement in HIV medical care was associated with being female and perceived HIV stigma. Women were less likely to be engaged in HIV medical care as compared to men, and persons who did not engage in medical care had higher average mean perceived HIV stigma scores than persons who engaged in HIV medical care.

Main Findings in the Disclosed Sample (N=120)

The results for the disclosed sample revealed that gender, educational level and employment status were important predictors of engagement in HIV medical care. Woman as compared to men, persons with less than a high school diploma as compared to persons with higher levels of education, and persons who were unemployed compared to persons unable to work were less likely to engage in HIV medical care. The psychosocial variables, denial and perceived HIV stigma were not significant predictors of engagement in HIV medical care as hypothesized.

Lessons Learned: Denial and Perceived HIV Stigma

Denial of HIV status in this study was examined as a coping mechanism that PLWHA use to deal with their HIV status (Carver, Scheier, & Weintraub, 1989). Denial has also been found to be a behavioral indicator of delay in entering HIV medical care (Goldbeck, 1997; Livneh, 2009). This study did not support denial as such a behavior indicator because denial was not related to engagement in HIV medical care. It was shown that a number of participants, newly diagnosed and out of care persons, experienced some level of denial in coping with HIV their diagnosis. Denial of HIV status and perceived HIV stigma were measured quantitatively in this study, but additional measures of qualitative data may help elucidate what PLWHA are experiencing after being diagnosis with HIV.

HIV stigma also affects PLWHA after diagnosis. PLWHA may allow societal and community norms to shape how they feel about themselves and subsequently affect their engagement in HIV medical care. Participants in this study may have knowledge or have experienced at least 4 types of stigma (1) perceived, (2) disclosure, (3) negative self-image, and (4) public attitudes about PLWHA based on the items contained on the perceived HIV stigma measure (Berger, Ferrans, & Lashley, 2001). Specifically in this study perceived HIV stigma and disclosure were examined. The findings from this study show that perceived HIV stigma and non-disclosure of HIV status is widespread in this sample. Thus suggests that PLWHA may fear being rejected if others know about their HIV status. Also, since many participants did not disclose their HIV status to others, this lack of disclosure could be related to a higher perception of HIV stigma.

Previous studies have reported a relationship between HIV stigma and disclosure of HIV status. In a meta-analysis examining the relationship between HIV status, stigma and social support, it was reported that greater HIV stigma was correlated with less disclosure of HIV status (Smith, R., Rossetto, K., & Peterson, B. L. 2008). In another study with HIV positive women with a history of abuse they reported that non-disclosure was a result of their fear of stigma and rejection from others (Clum et al., 2013). Perceived HIV stigma was suggested to be associated with disclosure of HIV status but depending on the relationship with the person. Derlega and colleagues found that PLWHA reported that perceived HIV stigma was one of the reasons they would not disclose to a parent, but it did not keep them from disclosing to a close friend (Derlega et al., 2002). HIV stigma in PLWHA is not a one-time event and may possibly cause them to experience the "spoiled identify" first theorized by Goffman with each new person that learns of their HIV positive status (Goffman, 1963). The experiences with HIV stigma may also differ by gender and SES.

Race, Gender, Socioeconomic Status (SES), Denial and Perceived HIV Stigma

Denial, stigma and fear are major barriers in dealing with HIV/AIDS in the African American communities (Foster, 2007). African Americans experience more HIV stigma than other races because they bear the greatest burden of the HIV disease (Galvan, et al., 2008). Stigma has been suggested to keep people from accessing care and employment opportunities that may ultimately affect their SES (CDC, 2011). In the bivariate analysis, there were significant gender differences on the denial and perceived stigma mean scale. Women who have disclosed their HIV status to others reported higher levels of denial and HIV stigma than men who have disclosed their HIV status to others. There were no significant differences in income by denial and perceived HIV stigma, but persons making less than $15000 per year reported a higher mean on the denial and perceived HIV scale than persons making greater than $15,000 per year. The analysis of variance for employment status showed there were no significant differences in denial and perceived HIV stigma, indicating that these three groups experienced comparable levels of denial and perceived HIV stigma. Denial and perceived HIV stigma does not differ based on a person's employment status for this sample.

In summary, among this sample of African American PLWHA, denial and perceived HIV stigma were experienced by a majority of participants. PLWHA experience both psychosocial factors whether they are out of care or newly diagnosed with HIV. Gender was an important variable in explaining how the population that had disclosed to others experienced perceived HIV stigma and denial. The results were similar for both variables with women who had disclosed to others reporting a greater level of denial and perceived HIV stigma than men who had disclosed to others. Women in this population may use denial as a way to cope with their HIV status and perceive more HIV stigma than men, and possibly need greater support to help them manage their HIV status. Finally, neither denial nor perceived HIV stigma were associated with engagement in HIV medical care.

Predisposing, Enabling and Need (PEN) Factors and Engagement in HIV Medical Care

The predisposing, enabling and need factors were selected because of their association with the model as well as with people living with HIV. The variables that were significantly correlated with engagement in HIV medical care were included in the logistic regression models.

In the total sample, none of the predisposing, enabling, and need factors were associated with engagement in HIV medical care. In the disclosed sample, the predisposing variables, gender and educational level variables were associated with engagement in HIV medical care.

Women compared to men were less likely to engage in HIV medical care. Participants who had less than a high school diploma were also less likely to engage in HIV medical care compared to participants with some college education or higher. These findings were similar to prior research with that reported gender (Aziz & Smith, 2011) and educational level (Kalichman et al., 1999; Rumptz et al., 2007; Saint-Jean et al, 2011) as barriers to utilization of HIV medical care for PLWHA.

Also in the disclosed sample, the enabling factor (employment status) was associated with engagement in HIV medical care. Persons who were able to work, but unemployed were less likely to engage in HIV medical care compared to persons who are unable to work. The majority of the sample had health insurance, was low income, unemployed and had a medical home. For the need factors there were no significant associations with engagement in HIV medical care. Also, in this population 86% of persons reported at least one barrier to accessing medical need and services. The barriers reported most include: housing, finances and transportation. In the bivariate analysis, out of care persons reported on average more barriers to care than newly diagnosed persons. Perhaps the reason no significant associations between barriers and engagement in medical care were found in this sample was because almost all participants experienced the same barriers to engaging in HIV medical care. In addition, they were African American, low income, had health insurance and a medical home. Also, the geographic location of this study could also be a reason there were no association of engagement in care with barriers, since Washington, DC has many HIV medical care and service providing organizations. These findings may be different from what might be found in rural areas where HIV resources are not as plentiful.

Andersen Behavioral Model and Engagement in HIV Medical Care

This study was guided by an adapted version of the Andersen Behavioral Model of Health Care Utilization. The model was adapted by adding psychosocial constructs denial and stigma to the predisposing factors and barriers to care scale and clinical indicators to the need factors. The study suggested that there is limited usefulness of adding these standardized measures to the ABM model when exploring how different factors influence engagement in HIV medical care for PLWHA.

First, adding denial to the Andersen Behavioral Model did not increase explanation of why PLWHA delay engaging in HIV medical care. Denial was not a significant predictor of engagement in HIV medical care for this population. Second, HIV stigma was added as a predisposing factor, and was tested for its influence on engagement in HIV medical care. Previously, Ulett and colleagues constructed a" blueprint to HIV treatment for success" which was also an adaptation of the ABM. In this blueprint, they suggested adding HIV stigma to the predisposing factors to evaluate its influence on HIV treatment in care (Ulett et al., 2009). The current tested HIV stigma as a predisposing factor and found that it had no significant relationship with engagement in HIV medical care, perhaps due to the limited sample size.

Significance of the Study

The continuum of engagement in HIV medical care describes the stages of care PLWHA can go through after being diagnosed with HIV. The continuum begins with HIV diagnosis to engagement in HIV medical care and the final step is HIV viral suppression (Cheever, 2007).

The continuum of care does not always progress from one step to the next and can be a very dynamic process. A PLWHA can be engaged in HIV medical care after diagnosis, fall out of care, and then be reengaged after a period of time.

This study looked at two population groups (out of care and newly diagnosed) across the HIV care continuum from diagnosis to engagement in HIV medical care. In this study, 28% of participants had not engaged in HIV medical care after 90 days. Examining engagement in care for newly diagnosed and out of care persons, 32% of out of care participants, and 18% of newly diagnosed participants had not engaged in HIV medical care. The results show that out of care persons were more likely at the end of 90 days to have not engaged in HIV medical care as compared to newly diagnosed persons. This population was categorized as out of care at enrollment and continued to remain less engaged in HIV medical care. It is important to break the cycle of low engagement among this population as well as keep newly diagnosed persons engaged in care. This research shows that gaps in care remain along the continuum of care for this population and the barriers associated with lack of engagement need to be identified and addressed.

While this dissertation assumed that the psychosocial variables denial and perceived HIV stigma were the reasons for the gaps in care, and they would be significant predictors of engagement in HIV medical care, this was not supported in this population. Denial and perceived HIV stigma did not predict engagement in HIV medical care. The results did reveal that disclosure of HIV status, the predisposing factors (gender and educational level) and the enabling factor (employment status) were associated with engagement in HIV medical care. The results suggest that in this population, different groups (newly diagnosed vs. out of care, men vs. women) and behaviors (disclosed vs. non-disclosed) may require different types of attention to keep them engaged in medical care as they progress along the continuum of HIV care. Engagement in care is a public health concern because if people are not engaged in HIV medical care, they are not receiving the benefits of treatment. This can lead to higher HIV viral loads, which are associated with poorer health outcomes and increase likelihood of transmission of HIV virus to others resulting in new HIV infections (Cheever, 2007; Cohen et al., 2011; Giordano et al., 2007).

There are approximately fifty thousand new HIV infections each year in the United States and according to the CDC, 90% of new infections in the U.S are the result of PLWHA who are not engaged in HIV medical care (CDC, 2003; Skarbinski et al., 2015). Lack of engagement in HIV medical care for PLWHA makes it difficult to reach the goals of the UNAIDS 2010 strategy of no new HIV infections. This was also the goal of World AIDS Day 2012, and a campaign initiated by AIDS United called “Getting to Zero (G2Zero)”. The goals of these campaigns are, zero new HIV infections, zero stigma and discrimination against PLWHA, and no more deaths from HIV/AIDS. In order to reach these goals set forth by these initiatives, it is important to that PLWHA are engaged and retained in HIV medical care. This dissertation study suggests that more attention should be aimed at out of care persons, people who have not disclosed their HIV status, and woman to strengthen treatment outcomes among persons who are at risk for not remaining in HIV medical care.

In this research study, it was found that both newly diagnosed and out of care persons experienced some level of denial and perceived HIV stigma. . This study administered the Berger’s HIV stigma scale, a standardized measure to examine HIV stigma, in this population but did not find any associations with engagement in HIV medical care. Examining how HIV stigma affects engagement in HIV medical care is becoming a national priority. One of the

National HIV/AIDS Strategy 2020 goals is to develop and annually report on measures designed to assess HIV related stigma experienced by persons living with HIV. If this this policy is implemented and HIV stigma screening is performed in medical care settings, new information about the relationship between HIV stigma and PLWHA's engagement in HIV medical care may be identified (Holtgrave, 2011).

Limitations of the Study

Findings should be interpreted in light of study limitations. First, only African-American PLWHA, newly diagnosed or out of care persons were recruited into the study; this may limit generalization of the findings to other races of HIV positive populations, PLWHA who are in continuous HIV medical care, and persons who are not enrolled in Positive Pathways.

Second, the sample was drawn from one urban geographic area in the United States with more HIV medical care and resources to engage PLWHA in medical care than many other urban areas; hence the results may not be generalizable to other metropolitan areas within the United States. Future studies with more variability in respect to race/ethnicity, healthcare systems, and geographic locations are needed.

Third, participant's self-reported answers to CHWs may have introduced social desirability bias. Participants may report answers that they think are more desirable to the CHW. Also, in regard to the dependent variable, participants could have introduced recall bias, where they may not recall the exact dates of their HIV medical visits or they could have falsely remembered dates. Hence, some engagement may not have been correctly revealed in the self-reports which could have introduced error into this measurement. CHW medical record review was used when participants could not recall or clearly report their medical visit history. The mix of participant self-report answers and CHW medical record review was thus used to capture the dependent variable. Participants self-report of medical appointments may not be as accurate as the medical record review and therefore less reliable. Hence, these mixed methods could also have introduced error into the measurement of engagement in medical care. This could diminish or inflate the effect found between the independent and dependent variables. The ideal method of data collection would have been to ask the CHW to provide medical record information for all clients but this was not feasible and would have placed an undue burden on them as many have large client caseloads.

Fourth, the 45-day assessment for collection of medical visits refers to the last 30 days although the period needed for measurement was 45 days. This may have reduced the number of appointments reported if participants were immediately linked to care within the first 15 days. Also, engagement in medical care was coded as no engagement if the participant was loss to follow-up or the medical visit information could not be obtained. Treating lost to follow-up as no engagement inflates the number of persons in this category and may affect the outcome. This decision was made because it was assumed that these individuals were not engaged in HIV medical care. Fortunately, there were few persons in this category and from all indications of reasons for loss to follow-up, engagement appeared highly unlikely among these persons.

Next, having a CHW in the study may diminish the extent of the association found between denial, perceived stigma and engagement in HIV medical care. The community health workers could have been instrumental in helping participants overcome denial, handle stigma, and engage in care, and this would possibly lessen the ability to detect associations between the study variables. Finally, the perceived HIV stigma scale was modified to include response items that were not included in the original scale. These response items include: don’t know, refused and I have not told anyone. This modification minimized the amount of missing data but substantially increased the number of cases for whom stigma could not be measured. This reduced the sample size and limited the power for evaluating the association between both stigma and the outcome variable.

Recommendations for Future Research

The findings from this study warrant further exploration. First, to better evaluate the degree to which perceived HIV stigma is associated with engagement in HIV medical care, future studies should include the Berger's HIV stigma subscale measure modified to include only those items that are applicable to all participants, which examines the level of perceived HIV stigma and not whether a person has disclosed their HIV status.

Second, inclusion of questions about disclosure status could help to determine if the PLWHA has ever disclosed their HIV status to others and if so, to whom they have disclosed to (i.e. parent, sexual partner, or close friend). This could provide a greater understanding of how perceived HIV stigma and disclosure may influence engagement in HIV medical care. Interventions can be developed aimed at increasing disclosure among African American PLWHA, as decreased disclosure leads to lower engagement in HIV medical care and can negatively affect the health outcomes of PLWHA.

Third, a longitudinal study that follows participants for longer than 90 days would help to better examine any causal relationships between variables. This study could also be conducted with and without a community health worker. Such a study could help determine if a CHW has an effect on the engagement in care and on the level of denial and perceived stigma experienced by participants. Finally, the development of gender based interventions, specifically for African American women with low educational level could help address specific barriers that this population faces when engaging in HIV medical care. As women make up one-fourth of

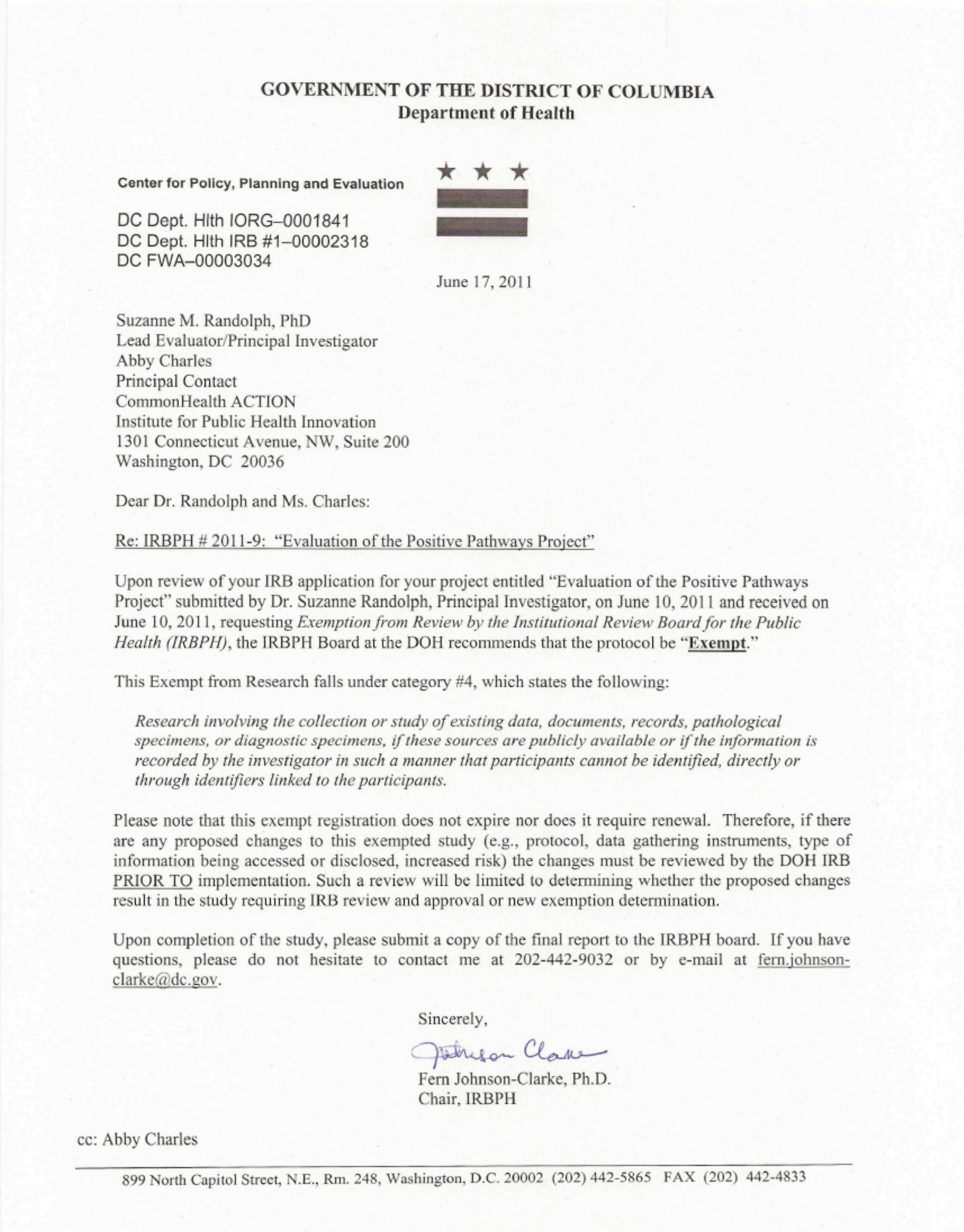
PLWHA in this country, and are more likely to delay entry into HIV medical care, it is important to develop interventions that will improve their engagement and retention in HIV medical care (Squires et al., 2011)

Conclusion

In summary, HIV treatment is lifelong and for PLWHA to benefit from treatment they must remain engaged in HIV medical care. The goal of this study was to determine whether the psychosocial factors denial and stigma were the main barriers keeping PLWHA from engaging in HIV medical care for PLWHA. The findings demonstrated that denial and perceived HIV stigma were not associated with engagement in HIV medical care for this population of African-American PLWHA when controlling for many other predisposing, enabling and need variables. However, the findings did reveal that disclosure of HIV status to others was related to engagement in the overall study sample. Among those who had disclosed their HIV status to others; gender, educational level, and employment status were significantly associated with engagement in HIV medical care. Denial, perceived stigma, and non-disclosure were found at high rates among the study sample. The research revealed the need to investigate further how denial, perceived HIV stigma, and disclosure together and separately affect engagement in HIV medical care. Understanding factors that decrease engagement in HIV medical care can inform the development of strategies to help keep PLWHA continuously engaged in HIV medical care.

Appendices

Appendix A: District of Columbia Department of Health IRB Approval Letter



GOVERNMENT OF THE DISTRICT OF COLUMBIA
Department of Health

Center for Policy, Planning and Evaluation

DC Dept. Hlth IORG–0001841
DC Dept. Hlth IRB #1–00002318
DC FWA–00003034

June 17, 2011

Suzanne M. Randolph, PhD
Lead Evaluator/Principal Investigator
Abby Charles
Principal Contact
CommonHealth ACTION
Institute for Public Health Innovation
1301 Connecticut Avenue, NW, Suite 200
Washington, DC 20036

Dear Dr. Randolph and Ms. Charles:

Re: IRBPH # 2011-9: "Evaluation of the Positive Pathways Project"

Upon review of your IRB application for your project entitled "Evaluation of the Positive Pathways Project" submitted by Dr. Suzanne Randolph, Principal Investigator, on June 10, 2011 and received on June 10, 2011, requesting *Exemption from Review by the Institutional Review Board for the Public Health (IRBPH)*, the IRBPH Board at the DOH recommends that the protocol be "**Exempt**."

This Exempt from Research falls under category #4, which states the following:

> *Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that participants cannot be identified, directly or through identifiers linked to the participants.*

Please note that this exempt registration does not expire nor does it require renewal. Therefore, if there are any proposed changes to this exempted study (e.g., protocol, data gathering instruments, type of information being accessed or disclosed, increased risk) the changes must be reviewed by the DOH IRB PRIOR TO implementation. Such a review will be limited to determining whether the proposed changes result in the study requiring IRB review and approval or new exemption determination.

Upon completion of the study, please submit a copy of the final report to the IRBPH board. If you have questions, please do not hesitate to contact me at 202-442-9032 or by e-mail at fern.johnson-clarke@dc.gov.

Sincerely,

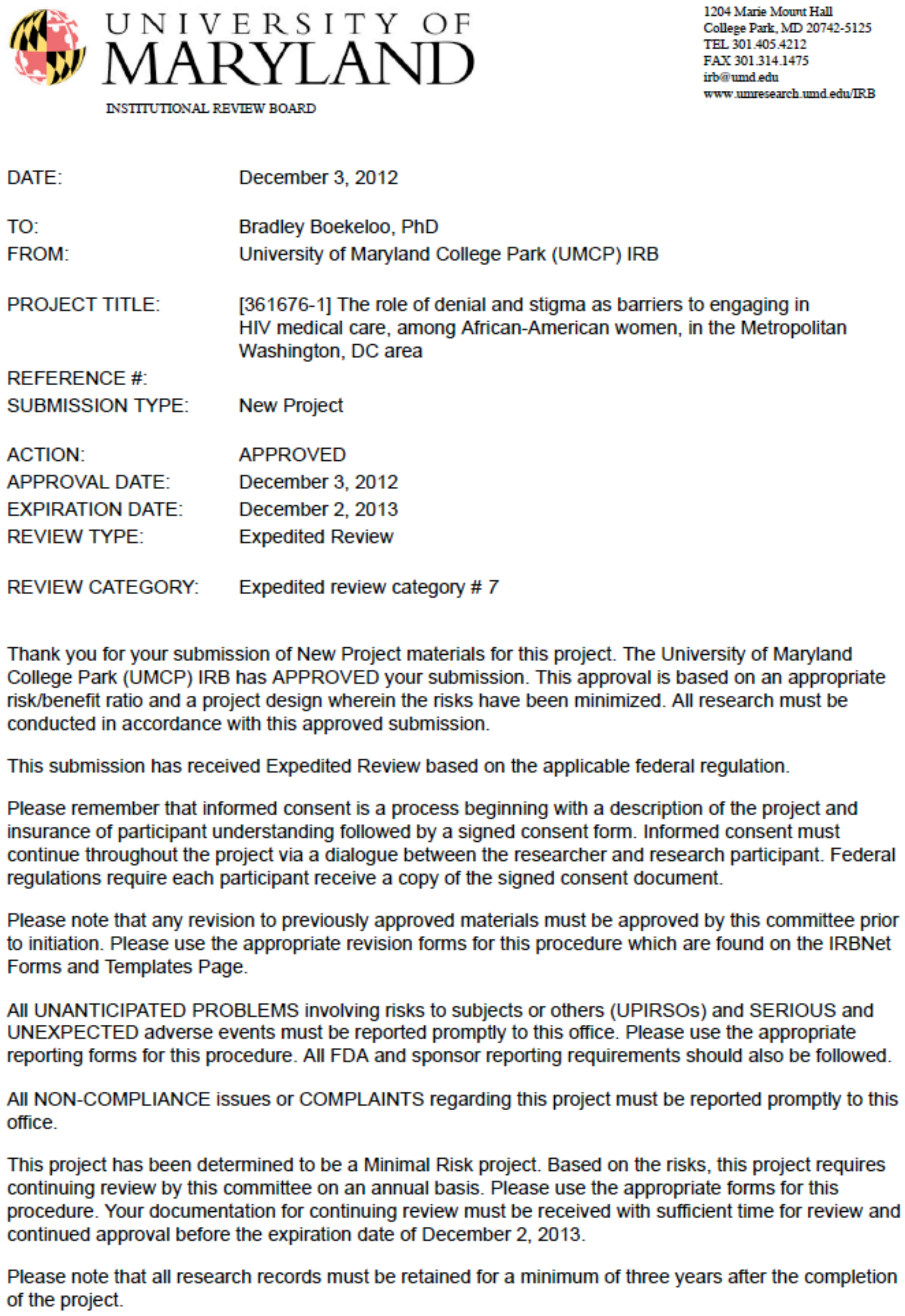
Johnson Clarke

Fern Johnson-Clarke, Ph.D.
Chair, IRBPH

cc: Abby Charles

899 North Capitol Street, N.E., Rm. 248, Washington, D.C. 20002 (202) 442-5865 FAX (202) 442-4833

Appendix B: University of Maryland at College Park IRB Approval Letter



UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

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DATE: December 3, 2012

TO: Bradley Boekeloo, PhD
FROM: University of Maryland College Park (UMCP) IRB

PROJECT TITLE: [361676-1] The role of denial and stigma as barriers to engaging in HIV medical care, among African-American women, in the Metropolitan Washington, DC area
REFERENCE #:
SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: December 3, 2012
EXPIRATION DATE: December 2, 2013
REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure which are found on the IRBNet Forms and Templates Page.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of December 2, 2013.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

Appendix C: Baseline Assessment

Date:
CHW ID:
Client Type/ Category:
Site ID:
Date client enrolled:

Positive Pathways HEALTH HISTORY QUESTIONNAIRE
All questions contained in this questionnaire are strictly confidential
and will become part of your medical record.

CLIENT ID *(XXXXXXX):* Age: DOB:
Marital status: ☐ Single ☐ Partnered ☐ Married ☐ Separated ☐ Divorced ☐ Widowed
Race/Ethnicity: (Check one or check "multiple races" if more than one race) : ☐ American Indian/ Alaska Native ☐ Asian ☐ Black, non-Hispanic ☐ Hispanic ☐ Native Hawaiian/Other Pacific Islander ☐ White, non-Hispanic ☐ Multiple races ☐ Don't Know ☐ Refused
Sex/Gender (Check One) ☐ Male ☐ Female ☐ Transgender Male to Female ☐ Transgender Female to Male ☐ Don't Know ☐ Refused
Education (Check one – Highest level reached/ completed) ☐ Less than HS ☐ HS Diploma or equivalent ☐ Some college or technical school ☐ College or Higher education ☐ Don't Know ☐ Refused
Income – Client's individual ☐ Less than $15,000 ☐ $15,000 to $24,999 ☐ $25,000 to $49,000 ☐ $50,000 to $74,999 ☐ 75,000 and up ☐ Don't Know ☐ Refused
Client's Health Insurance: ☐ None ☐ Yes: Specify type or name of plan ____
Is client eligible for Medicaid? ☐ No ☐ Yes
Does this client have a medical home (medical provider) ☐ No ☐ Yes
Employment status: ☐ Able to work, employed ☐ Able to work, not-employed ☐ Retired ☐ Unable to work
City: State: Ward: Zip Code:
(only answer about first meeting) How Did CHW First Engage Client (if multiple ways check "multimodal") : ☐ Street Outreach ☐ Social Media ☐ Peer outreach ☐ Multimodal ☐ No outreach conducted ☐ Don't Know ☐ Internal Referral
PERSONAL HEALTH HISTORY

Date of first positive HIV test (Mth/year): If the client does not have proof of HIV status was a test conducted?☐ No ☐ Yes Date of that confirmatory Test: Date of Lab Confirmation:

Has client's current partner(s) been tested for HIV? : ☐ No ☐ Yes ☐ Don't Know ☐ No current partner
Is partner seropositive? ☐ No ☐ Yes ☐ Don't Know ☐ N/A

Have you been to a medical visit with a provider who can prescribe medicine in an HIV care setting in the past 12 months? ☐ No ☐ Yes ☐ Don't Know

What were the dates of your HIV medical visits within the last 12 months? Please list all that apply:
___March 2011 ___April 2011 __May 2011__June 2011__ July 2011 __August 2011 __Sept 2011 __Oct 2011 __Nov 2011 __Dec 2011 __Jan 2012 __Feb 2012 __Mar 2012 __Apr 2012 __May 2012 __Jun 2012 ___ July 2012 ___ Aug 2012 ____Sep 2012 ___Oct 2012 ___Nov2012____Dec 2012

What is the client's CD4 count? (record either or both "self reported" or "clinic/lab") CD4 count –Self Reported? ________ Date of Count from self-report ___/___/_______ CD4 Count –Clinic/lab data? _______ Date of count from clinic/lab___/____/_______	Is client's CD4 count less than 500? ☐ No ☐ Yes Has client been prescribed HAART? ☐ No ☐ Yes

What is the client's Viral load? (record either or both "self-reported" or "clinic/lab")

Viral load–Self Reported? ________ Date of Count from self-report ___/___/_______

Viral load–Clinic/lab data? _______ Date of count from clinic/lab___/____/_______

STIGMA- These questions ask about some of your experiences, feelings, and opinions about how people with HIV feel and they you been treated.

I've felt that people avoided me because I have HIV : ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ I Haven't told anyone ☐ Refused

I've feared I would lose friends if they learned about my HIV: ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ Refused

I've thought other people were uncomfortable being with me because of my HIV: ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ I Haven't told anyone ☐ Refused

I've avoided getting treatment because someone might find out about my HIV: ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ Refused

CLIENT NEEDS		
What services do you currently need?		
☐ Drug and alcohol abuse treatment	☐ Dental services	☐ Food or other subsistence
☐ Housing or shelter	☐ HIV-related medical services	☐ Mental health services
☐ Employment training	☐ Non-HIV related medical services (for HIV or non-HIV reasons)	☐ Assistance with job seeking
☐ Child care	☐ Transportation	☐ Other family assistance (describe) ____________________ ___
☐ None	☐ Other (specify “other) ______________________________ ___	☐ Pharmacy or medication services (for HIV or non HIV reasons)
☐ Don’t know	☐ Refused	
Of the services the client said they need (those checked above) what services does the client report as needed most urgently? (Check only ONE most urgent response)		
☐ Drug and alcohol abuse treatment	☐ Dental services	☐ Food or other subsistence
☐ Housing or shelter	☐ HIV-related medical services	☐ Mental health services
☐ Employment training	☐ Non-HIV related medical services (for HIV or non-HIV reasons)	☐ Assistance with job seeking
☐ Child care	☐ Transportation	☐ Other family assistance (describe) __________________ _____
☐ None	☐ Other (specify “other) ______________________________ ___	☐ Pharmacy or medication services (for HIV or non HIV reasons)
☐ Don’t know	☐ Refused	
BARRIERS TO CARE		

Often people with HIV face barriers to getting HIV care. What factors make it hard for you to get care? Don’t read the categories below- let the client answer. If more than one factor is identified, ask: Of those factors which one poses the greatest barrier to care for you now? And check the box for question 2.		
☐ Lack of Money	☐ Distrust of medical system	☐ Immigration
☐ Homelessness	☐ Lack of perceived need	☐ Incarceration
☐ Drug use	☐ Stigma	☐ Competing priorities
☐ Fear	☐ Denial	☐ Transportation
☐ Location of care	☐ Lack of additional services	
☐ Structure of HIV testing	☐ Other (specify) ____________________________ __	
If more than one factor is identified as a barrier, which of these is the greatest barrier for the client now?		
☐ Lack of Money	☐ Distrust of medical system	☐ Immigration
☐ Homelessness	☐ Lack of perceived need	☐ Incarceration
☐ Drug use	☐ Stigma	☐ Competing priorities
☐ Fear	☐ Denial	☐ Transportation
☐ Location of care	☐ Lack of additional services	
☐ Structure of HIV testing	☐ Other (specify) ____________________________ __	
Would you say in general your health is? ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Don’t Know ☐ Refused		
DENIAL		
The questions below focus on how you deal with your HIV disease. Select the answer that best describes how often in the past month you have used each of the following to cope with your HIV.		
I say to myself “this isn’t real”. ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don’t Know ☐ Refused I refuse to believe that it has happened. ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don’t Know ☐ Refused I pretend that it hasn’t really happened. ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don’t Know ☐ Refused I act as though it hasn’t even happened. ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don’t Know ☐ Refused		
BARRIERS TO CARE		
Please indicate to what extent each of the following circumstances makes it difficult		

for you to receive the care, services or opportunities you wish to obtain.

Long distances to medical facilities and personnel.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

Medical personnel (e.g. physicians, nurses), who decline to provide direct care to persons with HIV/AIDS. ☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The lack of health care professionals who are adequately trained and competent in AIDS care
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The lack of transportation to access the services I need.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The shortage of psychologists, social workers and mental health counselors who can help address mental health issues.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The lack of psychological support groups for persons with HIV/AIDS.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The level of knowledge about HIV/AIDS among residents in the community.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

Community residents' stigma against persons living with HIV/AIDS.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The lack of employment opportunities for people living with HIV/AIDS.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

The lack of supportive and understanding work environments for people living with HIV/AIDS.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don't Know ☐ Refused

My personal financial resources.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major

Problem ☐ Don’t Know ☐ Refused

Lack of adequate and affordable housing.
☐ No problem at all ☐ Very slight problem ☐ Somewhat of a problem ☐ Major Problem ☐ Don’t Know ☐ Refused

PERCEIVED HIV STIGMA

These questions asks about some experiences, feelings, and opinions as to how people with HIV feel and how they are treated.

Have lost friends by telling them I have HIV.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Hurt by how people reacted to learning I have HIV.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

People avoid touching me if they know I have HIV.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Stopped socializing with some due to their reactions.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

People I care about stopped calling after learning.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

People seem afraid of me because I have HIV.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

People have physically backed away from me.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Some people who know have grown more distant.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

People who know tend to ignore my good points.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Don't want me around their children once they know.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

I feel set apart, isolated from the rest of the world.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

I regret having told some people that I have HIV.

☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Some fear they'll be rejected because of my HIV.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Some people act as though it's my fault I have HIV.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

As a rule, telling others has been a mistake.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Most with HIV are rejected when others learn.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

People have told me that getting HIV is what I deserve for how I lived my life.
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

When People learn you have HIV they look for flaws in your character
☐ Strongly disagree ☐ Disagree ☐ Agree ☐Strongly agree ☐ I Haven’t told anyone

Appendix D: 45, 90-day Assessments

Client ID:
Client Type /Category:
Client Status: (active, lost to care, graduated, re-engaged)
Client Status Comments:
CHW ID:
Site ID:
Date Client enrolled:

Positive Pathways Enrolled Client 45, 90-day Day Check IN
All questions contained in this questionnaire are strictly confidential and will become part of your medical record.

CLIENT ID (XXXXXXX): Age: DOB:
Please note any changes to client Demographics:
Marital status: ☐ Single ☐ Partnered ☐ Married ☐ Separated ☐ Divorced ☐ Widowed
Education (Check one – Highest level reached/ completed) ☐ Less than HS ☐ HS Diploma or equivalent ☐ Some college or technical school ☐ College or Higher education ☐ Don't Know ☐ Refused
Income – Client's individual ☐ Less than $15,000 ☐ $15,000 to $24,999 ☐ $25,000 to $49,000 ☐ $50,000 to $74,999 ☐ 75,000 and up ☐ Don't Know ☐ Refused
Client's Health Insurance: ☐ None ☐ Yes: Specify type or name of plan ____
Is client eligible for Medicaid? ☐ No ☐ Yes
Does this client have a medical home (medical provider) ☐ No ☐ Yes
Employment status: ☐ Able to work, employed ☐ Able to work, not-employed ☐ Retired ☐ Unable to work
City: State: Ward: Zip Code:
HEALTH Check –IN
Since the first meeting,

Has client's partner(s) been tested for HIV? : ☐ No ☐ Yes ☐ Don't Know Is partner seropositive? ☐ No ☐ Yes ☐ Don't Know	
Have you been to a medical visit with a provider who can prescribe medicine in an HIV care setting? ☐ No ☐ Yes ☐ Don't Know	
What was the date of your first HIV medical visit since we first met? ___/___/____ (CHW should verify this date)	
What were the dates of your HIV medical visits with a provider with prescribing privileges within the last 30 days? Please list all that apply: ___/_____/____ ____/_____/____ ____/____/______	
Have you met with an HIV case manager? ☐ No ☐ Yes ☐ Don't Know	
Does the client have a case management strategy/plan? ☐ No ☐ Yes ☐ Don't Know	
What was the date of this case management plan? ___/___/______	
What is the client's CD4 count? (record either or both "self reported" or "clinic/lab") CD4 count –Self Reported? ________ Date of Count from self-report ___/___/_______ CD4 Count –Clinic/lab data? _______ Date of count from clinic/lab___/____/_______	Is client's CD4 count less than 500? ☐ No ☐ Yes Has client been prescribed HAART? ☐ No ☐ Yes
What is the client's Viral load? (record either or both "self reported" or "clinic/lab") Viral load–Self Reported? ________ Date of Count from self-report ___/___/_______ Viral load–Clinic/lab data? _______ Date of count from clinic/lab___/____/______	
STIGMA	
I've felt that people avoided me because I have HIV : ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ I Haven't told anyone☐ Refused I've feared I would lose friends if they learned about my HIV: ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ Refused I've thought other people were uncomfortable being with me because of my HIV: ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don't Know ☐ I Haven't told anyone ☐ Refused	

I’ve avoided getting treatment because someone might find out about my HIV: ☐ Not at all ☐ Rarely ☐ Sometimes ☐ Often ☐ Don’t Know ☐ Refused		
CLIENT NEEDS		
Since our last meeting, have accessed any of the services that you needed? (CHW can list services that the client described at initial intake) ☐ No ☐ Yes ☐ Don’t Know		
What services did you access?		
☐ Drug and alcohol abuse treatment	☐ Dental services	☐ Food or other subsistence
☐ Housing or shelter	☐ HIV-related medical services	☐ Mental health services
☐ Employment training	☐ Non-HIV related medical services (for HIV or non-HIV reasons)	☐ Assistance with job seeking
☐ Child care	☐ Transportation	☐ Other family assistance (describe) ____________________
☐ None	☐ Other (specify “other) ______________________________ _	☐ Pharmacy or medication services (for HIV or non HIV reasons)
☐ Don’t know	☐ Refused	
What services do you currently need?		
☐ Drug and alcohol abuse treatment	☐ Dental services	☐ Food or other subsistence
☐ Housing or shelter	☐ HIV-related medical services	☐ Mental health services
☐ Employment training	☐ Non-HIV related medical services (for HIV or non-HIV reasons)	☐ Assistance with job seeking
☐ Child care	☐ Transportation	☐ Other family assistance (describe) ____________________
☐ None	☐ Other (specify “other) ______________________________ _	☐ Pharmacy or medication services (for HIV or non HIV reasons)
☐ Don’t know	☐ Refused	
Of the services the client said they need (those checked above) what services does the client report as needed most urgently? (check only ONE most urgent response)		
☐ Drug and alcohol abuse treatment	☐ Dental services	☐ Food or other subsistence

☐ Housing or shelter	☐ HIV-related medical services	☐ Mental health services
☐ Employment training	☐ Non-HIV related medical services (for HIV or non-HIV reasons)	☐ Assistance with job seeking
☐ Child care	☐ Transportation	☐ Other family assistance (describe) ________________
☐ None	☐ Other (specify “other) ____________________________ _	☐ Pharmacy or medication services (for HIV or non HIV reasons)
☐ Don’t know	☐ Refused	

BARRIERS TO CARE

Since our last meeting, have any of the barriers that you discussed been reduced/addressed? (CHW can list barriers that the client described at initial intake) ☐ No ☐ Yes ☐ Don’t Know

What Barriers have been addressed/reduced?

☐ Lack of Money	☐ Distrust of medical system	☐ Immigration
☐ Homelessness	☐ Lack of perceived need	☐ Incarceration
☐ Drug use	☐ Stigma	☐ Competing priorities
☐ Fear	☐ Denial	☐ Transportation
☐ Location of care	☐ Lack of additional services	
☐ Structure of HIV testing	☐ Other (specify) ____________________________	

What are the client’s barriers to getting HIV care?

☐ Lack of Money	☐ Distrust of medical system	☐ Immigration
☐ Homelessness	☐ Lack of perceived need	☐ Incarceration
☐ Drug use	☐ Stigma	☐ Competing priorities
☐ Fear	☐ Denial	☐ Transportation
☐ Location of care	☐ Lack of additional services	
☐ Structure of HIV testing	☐ Other (specify) ____________________________	

If more than one factor is identified as a barrier, which of these is the greatest barrier to care for you now?

☐ Lack of Money	☐ Distrust of medical system	☐ Immigration
☐ Homelessness	☐ Lack of perceived need	☐ Incarceration
☐ Drug use	☐ Stigma	☐ Competing priorities
☐ Fear	☐ Denial	☐ Transportation

☐ Location of care	☐ Lack of additional services	
☐ Structure of HIV testing	☐ Other (specify) ______________________________	
Would you say in general your health is? ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Don’t Know ☐ Refused		

Appendix E: Participant Responses to Denial and Perceived HIV Stigma Measures

TableE.1 Responses to Denial scale reported by participants (N=262)

Denial	**Not at all N (%)**	**Rarely N (%)**	**Sometimes N (%)**	**Often N (%)**	**Missing N (%)**
I say to myself this isn't real	163(62)	8(3)	39(15)	20(7)	32(12)
I refuse to believe that is has happened	175(67)	6(2)	29(11)	20(7)	32(12)
I pretend that it really hasn't happened	174(66)	6(2)	31(12)	21(8)	30(12)
I act as though it hasn't even happened	172(66)	7(2)	31(12)	18(7)	34(13)

Table E.2 Responses to Perceived HIV stigma Scale reported by percentage of participants (N=262)

Perceived HIV Stigma	Strongly Disagree N (%)	Disagree N (%)	Agree N (%)	Strongly Agree N (%)	I Haven't Told Anyone N (%)	Missing N (%)
I have lost friends by telling them I have	68(56)	23(19)	21(18)	9(8)	104(40)	0
I have lost friends by telling them I have HIV	67(26)	23(9)	21(8)	9(3)	104(40)	38(15)
I have been hurt by how people reacted to learning I have HIV	63(24)	16(6)	22(8)	19(7)	104(40)	38(15)
People avoid touching me if they know I have HIV	73(28)	28(11)	9(3)	7(3)	101(39)	44(17)
I stopped socializing with some due to their reactions	67(26)	18(7)	20(8)	15(6)	102(39)	40(15)
People I care about stopped calling after learning I have HIV	73(28)	27(10)	11(4)	9(3)	101(39)	41(16)
People seem afraid of me because I have HIV	75(29)	20(8)	14(5)	8(3)	102(39)	43(16)
Some people who know my HIV status have grown more distant	72(28)	22(8)	19(7)	10(4)	101(39)	38(14)
People have physically backed away from me	66(25)	30(12)	15(6)	14(5)	97(37)	40(15)
People who know my HIV status tend to ignore my good points	75(29)	20(8)	15(6)	10(4)	96(37)	46(18)

Some People Don't want me around children once they know my HIV status	76(29)	23(9)	11(4)	5(2)	104(40)	43(16)
I feel set apart, isolated from the rest of the world	68(26)	22(8)	26(10)	22(8)	83(38)	41(16)
I regret having told people that I have HIV	70(27)	18(7)	15(6)	22(8)	96(37)	41(16)
Some people feel they will be rejected because of my HIV status	69(26)	20(8)	17(7)	10(4)	98(37)	48(18)
Some people act as though it's my fault I have HIV	69(26)	22(8)	14(5)	8(3)	103(39)	46(18)
As a rule, telling others about my HIV Status has been a mistake	68(26)	24(9)	12(5)	22(8)	96(37)	40(15)
Most people with HIV are rejected when others learn of their HIV status	62(24)	20(8)	33(13)	25(10)	82(31)	40(15)
People have told me that getting HIV is what I deserve for how I lived my life	74(28)	25(10)	9(3)	14(5)	98(37)	42(16)
When people learn you have HIV they look for flaws in your character	73(28)	20(8)	21(8)	12(5)	91(35)	45(17)

Participant Responses on Denial Scale (N=120)

Table describes the participant responses on the denial mean scale for the disclosed sample. The respondents were asked to select the answer that best describes, “How often in the past month have you used each of the following to cope with their HIV.” The majority of the sample (69%) responded that they had not been doing any of the four items in the denial scale. The item mentioned the most by participants was “I say to myself this is not real” (22%).

Table E.3 Responses to Denial Scale by persons who disclosed HIV status (N=120)

Denial	**Not at all N (%)**	**Rarely N (%)**	**Sometimes N (%)**	**Often N (%)**	**Missing N (%)**
I say to myself this isn't real	94(78)	3(3)	15(13)	6(5)	2(1)
I refuse to believe that is has happened	102(85)	5(4)	6(5)	5(4)	2(2)
I pretend that it really hasn't happened	98(82)	4(3)	12(10)	4(3)	2(2)
I act as though it hasn't even happened	97(81)	4(3)	9(8)	7(6)	3(3)

Table E.4 Responses for Perceived HIV stigma by persons who disclosed HIV status (N=120)

Perceived HIV Stigma	Strongly Disagree N (%)	Disagree N (%)	Agree N (%)	Strongly Agree N (%)	Missing N (%)
I have lost friends by telling them I have HIV	67(56)	23(19)	21(18)	9(8)	0
I have been hurt by how people reacted to learning I have HIV	63(53)	16(13)	20(17)	16(13)	5(4)
People avoid touching me if they know I have HIV	72(60)	28(23)	8(7)	4(3)	8(7)
I stopped socializing with some due to their reactions	65(54)	18(15)	18(15)	14(12)	5(4)
People I care about stopped calling after learning I have HIV	70(58)	26(22)	11(9)	5(4)	8(7)
People seem afraid of me because I have HIV	74(62)	20(17)	14(12)	4(3)	8(7)
Some people who know my HIV status have grown more distant	70(58)	22(18)	17(15)	6(5)	5(4)
People have physically backed away from me	64(52)	26(22)	15(13)	8(7)	7(6)
People who know my HIV status tend to ignore my good points	69(58)	20(17)	13(11)	8(7)	10(8)
Some People don't want me around children once they know my HIV status	72(60)	21(18)	11(9)	4(3)	12(10)

I feel set apart, isolated from the rest of the world	62(52)	21(18)	19(16)	12(10)	6(5)
I regret having told people that I have HIV	64(53)	17(14)	13(11)	17(14)	9(8)
Some people feel they will be rejected because of my HIV status	67(56)	17(14)	17(14)	7(6)	12(10)
Some people act as though it's my fault I have HIV	67(56)	21(18)	14(12)	6(5)	12(10)
As a rule, telling others about my HIV Status has been a mistake	68(57)	22(8)	12(10)	11(9)	7(6)
Most people with HIV are rejected when others learn of their HIV status	62(52)	19(16)	23(19)	10(8)	6(5)
People have told me that getting HIV is what I deserve for how I lived my life	73(61)	24(20)	9(8)	6(5)	8(7)
When people learn you have HIV they look for flaws in your character	71(59)	19(16)	16(13)	4(3)	10(8)

Appendix F: Barriers to Care Scale Results

Table 1 presents the participants responses on the barriers to care scale. Participants reported the extent that each of the following circumstances made it difficult for them to receive the HIV medical care, services or opportunities they wished to obtain. The most reported barriers for this population were related to their personal finances, followed by housing and transportation. The four items pertaining to community stigma and work environment knowledge were removed from the barriers to care scale for the analysis. These items contained a high number of missing values, because participants answered ‘refused’ or ‘don’t know. The researcher believed that the participants did not fully understand the questions or they did not apply to them. The modified 8-item scale was used in all subsequent analysis.

Table 1 Responses for Barriers to care scale reported by participants (N=262)

Barriers to Care	No problem at all N (%)	Very slight problem N (%)	Somewhat of a problem N (%)	Major Problem N (%)	Missing N (%)
Long distances to medical facilities and personnel	181(69)	19(7)	21(8)	8(3)	33(13)
Medical personnel (e.g. physicians, nurses), who decline to provide direct care to persons with HIV/AIDS	195(74)	13(5)	5(2)	8(3)	41(16)
The lack of health care professionals who are adequately trained and competent in AIDS care	196(75)	12(5)	4(2)	6(2)	44(16)
The lack of transportation to access the services I need.	121(46)	19(7)	40(15)	52(20)	30(12)

The shortage of psychologists, social workers and mental health counselors who can help address mental health issues	188(72)	12(5)	7(3)	5(2)	50(19)
The lack of psychological support groups for persons with HIV/AIDS	171(65)	10(4)	11(4)	9(3)	61(23)
The level of knowledge about HIV/AIDS among residents in the community	101(38)	12(5)	20(8)	34(13)	95(36)**
Community residents' stigma against persons living with HIV/AIDS	89(34)	14(5)	23(9)	41(16)	95(36)**
The lack of employment opportunities for people living with HIV/AIDS	100(38)	12(5)	13(5)	17(7)	120(46)**
The lack of supportive and understanding work environments for people living with HIV/AIDS	106(41)	6(2)	12(5)	20(8)	118(45)**
My personal financial resources	65(25)	32(12)	35(13)	98(37)	32(12)
Lack of adequate and affordable housing	73(28)	23(9)	41(16)	88(34)	37(14)

Note: ** items that will be removed from scale and not used in data analysis

<u>Rate of Barriers to Care in total sample</u>

The rate of barriers to care in total population was calculated using the 12 items contained in the Barriers to Care Scale. A mean BAC scale was created with the 12 items. After the creation of the scale the responses were dichotomized with “1” set to “0” and all other scores greater than 1, were set to “1”. All scores of 0 represented ‘no barriers to care’ and any score 1 or greater denoted the ‘presence of a barrier’. The total participants that reported no barriers was (N=33) and the total that reported some barriers a score of greater than 1 was (N=204). BAC was defined as participant saying yes to at least 1 of the BAC items. **The total sample size was 237. To calculate the rate of barriers in the population the frequencies were summed to obtain the total numbers of 'yes' responses to each of the items and the total of 'no' responses. The total yes responses were divided by the total (yes responses + no responses) to obtain the total rate of barriers in the population. The rate of barriers reported in the population was calculated at 86%. The majority of the population has experienced at least one barrier to engagement in medical care and services in the month before enrollment.

Table 2. Rate of barriers to care within the total sample (N=262)

BAC	N (%)*
Long distances to medical facilities and personnel	48(18)
Medical personnel (e.g. physicians, nurses), who decline to provide direct care to persons with HIV/AIDS	26(10)
The lack of health care professionals who are adequately trained and competent in AIDS care	22(9)
The lack of transportation to access the services I need	111(42)
The shortage of psychologists, social workers and mental health counselors who can help address mental health issues	24(10)
The lack of psychological support groups for persons with HIV/AIDS	29(11)
The level of knowledge about HIV/AIDS among residents in the community	66(26)
Community residents' stigma against persons living with HIV/AIDS	78(30)
The lack of employment opportunities for people living with HIV/AIDS	42(17)
The lack of supportive and understanding work environments for people living with HIV/AIDS	38(15)

My personal financial resources	165(62)
Lack of adequate and affordable housing	152(59)

Note:* Very Slight Problem, Somewhat of a problem, Major Problem

Difference in BAC by client type with total sample

To determine whether there were differences in the level of BAC by client type chi-square analysis was conducted. The out of care persons reported higher levels of barriers to care than newly diagnosed persons (88% vs. 79%) respectively. This difference was not statistically significant. X^2 (1) =3.2, p=0.06.

Table 3. Difference in BAC by client type with total sample (N=262)

Participant Response, N (%)			
Responses	Client Type		Total
	Newly Diagnosed	Out of Care	
No BAC	12(21%)	21(12%)	33(14%)
Yes BAC	45(79%)	159(88%)	204(86%)

Note: X^2 (1) =3.2, p=0.06

Descriptive statistics and Cronbach's alpha for BAC Scale (N=262)

Table 4. presents the descriptive statistics and Cronbach's analysis for the BAC measure. The scale was created by taking the mean of the 12 items for the total mean BAC scale. The reported average score on the BAC mean scale was 1.83(SD=.75). The BAC total scale scores ranged from 1 to 4. Higher scores indicate more barriers to obtaining HIV medical care and services for participants. Cronbach's alpha was calculated to confirm the internal reliability for the scale in this population, which was .91.

Table 4. Descriptive statistics and Cronbach's alpha for BAC Scale (N=262)

Scale	N	M (SD)	Observed Range	Theoretical Range	Cronbach's Alpha

BAC Mean Scale	237	1.83 (0.75)	1-4	1-4	0.91

Correlations with BAC Mean Scale

Pearson’s correlations were conducted to determine the relationship between the BAC Mean scale and study variables (Table 5). The BAC mean scale was negatively correlated to medical home, income, being employed $p<.01$. In addition ,BAC mean scale was positively correlated with gender, client needs, client barriers, marital status, denial mean scale and perceived HIV stigma mean scale $p<.01$.

Table 5 Pearson Correlations between BAC and study variables (N=262)

Variable	**BAC Scale**
1.Client Type	0.05
2.Age	0.12
3.Female Gender	0.17^{**}
4. Health Insurance	-0.06
5. Medical Home	-0.13
6. CD4 Count	0.009
7. HIV Viral Load	0.03
8. Engagement	-0.28^{**}
9.Income	0.25^{**}
10.Client Needs	0.26^{**}
11.Client Barriers	$-.024^{**}$
12. Able to Work, Employed vs. Unable to work	0.07
13.Able to Work, Unemployed vs. Unable to Work	0.27^{**}
14. Single/Separated/Divorced /Widowed vs. Partnered Married	-0.04
15. Some College/Tech School /College Education or Higher vs. less than High School	0.005
16.High school/GED vs. less than High School	-0.13
17. Quality of Life	-0.12
18.Disclosure	0.25^{**}
19.Denial Mean Scale	0.44^{**}
20.BAC Mean Scale	1

Logistic Regression

Logistic regression analysis was conducted to examine the effects of Barriers to care on engagement in HIV medical care.

Unadjusted Model

Unadjusted Logistic regression analysis was conducted to assess the direct association of BAC and engagement in HIV medical care. Engagement in HIV medical care was regressed on the BAC mean scale (Table 6). Barriers to care was not a significant predictor of engagement in HIV medical care for this population, (OR=1.1; 95%CI [0.72, 1.7]; p=.64).

Table 6: Unadjusted Logistic regression analysis examining the direct effect of BAC on engagement in HIV medical care (N=262).

Variables	B	S.E.	Wald	Df	p-value	O.R.	95% CI
BAC Mean Scale	0.10	0.22	0.22	1	0.64	1.1	0.72- 1.7
Constant	0.85	0.41	4.2	1	0.04	2.4	

Adjusted Models

Forward Stepwise Model

Adjusted logistic regression was conducted using forward stepwise method, engagement in HIV medical care was regressed on BAC, client type and all variables significantly associated with engagement in HIV medical care from the bivariate analysis. Disclosure of HIV status to others was the only significant predictor of engagement in HIV medical care (OR= 2.2; 95% CI [1.1, 4.2]; p=0.02). Persons who disclosed HIV status to others were 2.2 times more likely to engage in HIV medical care compared to those persons who had not disclosed their HIV status to others (Table 7). No additional predictors were found to be statistically significant.

Table 7 Adjusted Logistic regression analysis examining the effect of BAC on engagement in HIV medical care Adjusted for variables associated with BAC (N=262)

Variables	B	S.E.	Wald	df	Sig.	O.R.	95% CI
Disclosure	0.78	0.34	5.4	1	0.02	2.2	1.1- 4.2
Constant	0.59	0.23	6.2	1	0.01	1.8	

Enter Model

Adjusted logistic regression model using the enter method was conducted with all variables identified as significantly associated with engagement in HIV medical care from the bivariate analysis. Engagement in HIV medical care was regressed on BAC mean scale with the covariates (client type, medical home, marital status (partnered/married), mean denial scale and disclosure). Disclosure of HIV status to others was a significant predictor of engagement in HIV medical care (OR= 2.6; 95% CI [1.3, 5.3]; p=.007). Mean BAC scale was not a significant predictor of engagement in HIV medical care (p=.31).

Table 8. Adjusted Logistic Regression(Enter Method)Engagement in HIV medical Care with Barriers to Care with total sample (N=262)

Variables	B	S.E.	Wald	df	p-value	O.R.	95% CI
Client Type	-0.78	0.46	2.9	1	0.09	0.46	0.18-1.1
Medical Home	-0.42	0.40	1.1	1	0.29	0.66	0.30-1.4
Partnered/Married	0.89	0.49	3.3	1	0.68	2.43	0.94-6.3
Disclosure	0.96	0.36	7.2	1	0.007	2.61	1.3-5.3
BAC Mean Scale	0.26	0.26	1.0	1	0.31	1.30	0.78-2.2
Constant	0.82	0.74	1.2	1	0.27	2.27	

BARRIERS TO CARE (N=120)

Table 9. presents the participants responses on the modified-barriers to care scale. The community related and work environment barriers to care questions were removed from analysis because of high number of missing data. Participants reported the extent that each of the following circumstances made it difficult for them to receive the HIV medical care, services or opportunities they wished to obtain. The most reported barriers for this population were related to personal finances, housing and transportation. The four items pertaining to community stigma and work environment knowledge were removed from the barriers to care scale. These items contained high numbers of missing values, where participants answered ‘refused’ or ‘don’t know’. This lead the researcher to believe that participants did not fully understand the questions or that they did not apply to participants. The modified 8-item scale was used in all subsequent analysis.

Table 9 .Responses to modified-BAC by persons who Disclosed HIV status (N=120)

Barriers to Care	No problem at all N (%)	Very slight problem N (%)	Somewhat of a problem N (%)	Major Problem N (%)	Missing N (%)
Long distances to medical facilities and personnel	89(74)	13(11)	11(9)	3(3)	4(3)
Medical personnel who decline to provide direct care to persons with HIV/AIDS	98(82)	9(8)	4(3)	4(3)	5(4)
The lack of health care professionals who are adequately trained and competent in AIDS care	98(82)	10(8)	2(2)	5(4)	5(4)
The lack of transportation to access the services I need	79(66)	12(10)	11(9)	15(13)	3(3)

The shortage of psychologists, social workers and mental health counselors who can help address mental health issues	97(81)	9(8)	4(3)	3(3)	7(6)
The lack of psychological support groups for persons with HIV/AIDS	92(77)	6(5)	8(7)	4(3)	10(8)
My personal financial resources	45(38)	18(15)	17(14)	38(32)	2(2)
Lack of adequate and affordable housing	30(25)	13(11)	21(18)	50(42)	6(5)

** Note- community related barriers to care questions were removed from analysis because of high number of missing data.

Rate of BAC-Disclosed Sample (N=120)

The rate of barriers to care in total population was calculated using the 8 items contained in the modified Barriers to Care Scale. A mean BAC scale was created with the 8 items. After the creation of the scale the responses were dichotomized with “1” set to “0” and all other scores greater than 1, were set to “1”. All scores of 0 represented ‘no barriers to care’ and any score 1 or greater denoted the ‘presence of a barrier’. BAC was defined as a participant saying yes to at least 1 of the BAC items. The total responses reported for no barriers was (N=37) and the total that reported some barriers had a score of greater than 1 was (N=83). The total sample was 120. To calculate the rate of barriers to care in the population the frequencies were summed to obtain the total numbers of ‘yes’ responses to each of the items and the total of ‘no’ responses. The total yes responses were divided by the total (yes responses + no responses) to obtain the total rate of barriers in the population. The rate of barriers reported in the population was calculated at 69% in this population. A large number of participants had experienced at least one barrier to obtaining HIV medical care and services in the month before enrollment.

Table 10. Rate of modified BAC among participants who disclosed their HIV status (N=120)

BAC	N (%)[*]
Long distances to medical facilities and personnel	27(23)
Medical personnel who decline to provide direct care to persons with HIV/AIDS	17(14)
The lack of health care professionals who are adequately trained and competent in AIDS care	17(14)
The lack of transportation to access the services I need	38(32)
The shortage of psychologists, social workers and mental health counselors who can help address mental health issues	16(10)
The lack of psychological support groups for persons with HIV/AIDS	18(14)
My personal financial resources	73(61)
Lack of adequate and affordable housing	84(71)

Note:[*] Very Slight Problem, Somewhat of a problem, Major Problem

Difference in BAC by client type among persons who disclosed HIV status

To determine whether there were differences in the level of BAC by client type chi-square analysis was conducted. The out of care persons reported higher level of barriers to care than newly diagnosed persons (86 vs. 56%) respectively. This difference was statistically significant. (X^2 (1) =8.5, p=0.009). Out of care persons reported greater barriers when trying to access HIV medical care and services then newly diagnosed persons.

Table 11. Difference in BAC, by client type among persons who disclosed HIV status (N=120).

Participant Response, N (%)			
Responses	Client Type		Total
	Newly Diagnosed	Out of Care	
No BAC	7(44%)	14(14%)	21(18%)
Yes BAC	9(56%)	88(86%)	97(82%)

X^2 (1) =8.5, p=0.009

Table 12 presents the descriptive statistics and Cronbach's analysis was calculated for the modified-BAC scale with the disclosed sample. The reported average score on the modified BAC mean scale was 1.69(SD=.65).The modified- BAC mean total scale scores ranged from 1 to 4. Cronbach's alpha was calculated to confirm the internal reliability for the scale in this population, which was 0.81.

Table 12. Descriptive statistics and Cronbach's alpha for BAC Scale disclosed sample (N=120)

Scale	**N**	**M (SD)**	**Observed Range**	**Theoretical Range**	**Cronbach's Alpha**
BAC Mean Scale	118	1.69(0.65)	1-4	1-4	0.81

Correlations analysis with BAC and other study variables (N=120)

Bivariate correlations were conducted with the disclosed sample (N=120) to determine the relationship between modified BAC mean scale and all other study variables (Table 13). BAC was positively correlated client type, gender, client needs, client barriers, denial mean scale, HIV perceived stigma mean scale ($p<.05$). BAC was negatively correlated with medical home, income, able to work, employed, and engagement in HIV medical care. Higher BAC scores were associated with higher perceived HIV stigma mean and denial mean scores ($p<0.01$).

Table 13 Correlation analysis of study variables with Denial and Perceived HIV stigma, BAC for persons who Disclosed HIV status (N=120)

Variables	BAC
1.Client Type	$.18^{*}$
2.Age	-.009
3.Female Gender	$.19^{*}$
4. Health Insurance	.06
5. Medical Home	$-.22^{*}$
6. CD4 Count	-.09
7. HIV Viral Load	.07
8. Engagement	-.06
9.Income	$-.29^{**}$
10.Client Needs	$.28^{**}$
11.Client Barriers	$.22^{*}$
12. Able to Work, Employed vs. Unable to work	$-.27^{**}$
13.Able to Work, Unemployed vs. Unable to Work	.09
14.Single/Separated/Divorced /Widowed vs. Partnered Married	.09
15. Some College/Tech School /College Education or Higher vs. less than High School	.02
16.High school/GED vs. less than High School	-.005
17. Quality of Life	.03
18.Disclosure	$.34^{**}$
19.Denial Mean Scale	$.58^{**}$
20.BAC Mean Scale	1

*p< 0.05 level **p< 0.01 level

Logistic Regression Analysis with BAC-disclosed sample (N=120)

Unadjusted Model

Unadjusted logistic regression analysis was conducted to assess the direct association of BAC and engagement in HIV medical care. Engagement in HIV medical care was regressed on the modified-BAC mean scale (Table 14). Barriers to care was not a significant predictor of engagement in HIV medical care for this population (OR=0.90; 95 % CI [0.49, 1.6]; p=.74).

Table 14. Unadjusted Logistic regression analysis examining the direct effect of BAC on engagement in HIV medical care for disclosed sample (N=120).

Variables	B	S.E.	Wald	df	p-value	O.R.	95% CI
BAC Mean Scale	-0.10	0.31	0.11	1	0.74	0.90	0.49-1.6
Constant	1.5	0.57	6.7	1	0.009	4.43	

Adjusted Models

Forward step wise

Adjusted logistic regression was conducted using forward stepwise method examining the effect of BAC on engagement in HIV medical care for persons who disclosed their HIV status. Engagement in HIV medical care was regressed on the modified BAC scale. The covariates in the model included client type, gender, medical home, educational level, and employment status. Educational level was the only significant predictor of engagement in HIV medical care OR=4.5; 95%CI [1.3, 15.4]; p=.02.

Table 15. Adjusted Logistic regression (Forward Stepwise model) for BAC and Engagement in HIV medical care for persons who disclosed HIV status (N=120)

Variables	B	S.E.	Wald	df	p-value	O.R.	95% CI
Some College/Tech School/College Education or Higher	1.5	0.63	5.8	1	0.02	4.5	1.3-15.4
Constant	0.86	0.16	27.4	1	0.00	2.4	

Enter method

Adjusted logistic regression model using the enter method was conducted with the modified BAC scale and covariates (Table 16). Engagement in HIV medical care was regressed on the modified- BAC mean scale and the following covariates (client type, gender, medical home, employment status, and educational level). Mean BAC scale was not a significant predictor of engagement in HIV medical care (p=. 53).

Table 16. Adjusted Logistic regression of BAC and engagement in HIV medical care for persons who Disclosed HIV status (N=120)

Variables	B	S.E.	Wald	df	p-value	O.R.	95% CI
Client Type	-0.65	0.42	2.38	1	0.12	0.52	0.23-1.2
Gender	-0.84	0.33	0.06	1	0.80	0.92	0.48-1.8
Medical Home	-0.54	0.38	2.02	1	0.16	0.58	0.28-1.2
Some College/Tech School/College Education or Higher	1.53	0.63	5.88	1	0.02	4.63	1.3-15.9
Able to Work, Unemployed	-0.36	0.34	1.15	1	0.28	0.69	0.36-1.3
BAC Mean Scale	0.16	0.26	0.39	1	0.53	1.18	0.71-1.9
Constant	1.72	0.69	6.14	1	0.01	5.58	

Barriers to care was not an independent predictor of engagement in HIV medical care. In the adjusted models with the disclosed sample, educational level was the only the significant predictor of engagement in HIV medical care. Persons with some college or higher were more likely to engage in HIV medical care than persons with less than high school education.

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