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#### **Abstract**

**Background.** The stress of receiving the diagnosis of and living with HIV has a profound impact on the health outcomes and treatment status of people who live with HIV (PLWH). Stress management invokes a process of assessment and adoption of distinct coping strategies to manage specific HIV related stress. Although past studies have established the relationship between stress, coping strategies and HIV clinical outcomes, there is a lack of literature detailing the coping strategies used by men who have sex with men and are living with HIV (MSM-LWH) across HIV continuum stages. This research study attempts to address this gap and provide more insight toward future interventions aimed at improving retention and treatment adherence among minority men MSM-LWH. **Methods.** The study team conducted interviews with 84 MSM-LWH in 2014. This study presents an analysis of 84 in-depth qualitative interviews with MSM-LWH living in five different cities: Atlanta, Baltimore, Chicago, Los Angeles and Washington, D.C. Study participants were then categorized into three HIV care continuum group typologies: careengaged, care-inconsistent and care-detached.

Results. This study identified differences and similarities in stress-related coping strategies across the three care continuum groups. Care-engaged MSM-LWH were more likely to use problem-focused strategies that positively contribute to health promoting behaviors, while care-inconsistent and care-detached utilized emotion-focused coping strategies that diminish their ability to positively cope with their HIV status. High levels of primary (perceived threat) and secondary (perceived control, self-efficacy) appraisal had implications for use of effective coping strategies and better HIV care outcomes. Conclusions. Problem-focused coping strategies were predominantly utilized by MSM-LWH categorized as care engaged who adopted effective HIV care behaviors; Emotion-focused coping strategies were consistently used by MSM-LWH in the other categories who exhibited behavior detrimental to their health. Study findings also imply that future care and treatment adherence interventions need to address coping issues and be tailored to the needs of MSM-LWH in each care group.

#### Acknowledgements

The author would like to acknowledge the contributions of Paula Frew, PhD, MA, MPH and James Carey, PhD, MPH. The author would also like to thank the original research team and experts who were involved in the development and data collection of this research project: Damian Denson, PhD, MPH; Deborah Gelaude, MA; Nicole Pitts, BS; Robert Swayzer, DrPH; Aisha Wilkes, MPH; Alisu Schoua-Glusberg, PhD; Katherine Kenward, RN, MS; Susan Berkowitz, PhD; Elizabeth Gall, MS; Diane Saint-Victor, MPH; and Jay T. Schamel, BS. Funding for the original research and data collection was provided by the Centers for Disease Control and Prevention under a contract awarded to Research Support Services, Inc. (200-2013-57341/00001).

Permission to use the original data analyzed for this thesis was provided by the Centers for Disease Control and Prevention. Finally, the author thanks Vincent Fenimore, PhD, Fauzia Malik, MA, and Laura Randall, MPH for their support and editorial assistance.

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#### **Chapter 1: Introduction**

#### **Problem Definition**

HIV Incidence and Prevalence Rates in the US. According to the Centers of Disease Control and Prevention (CDC), there are approximately 1.2 million people living with HIV (PLWH) in the United States (Bradley et al., 2014; Hall et al., 2015). Although the HIV incidence among the general U.S. population has decreased by 19% over the past decade, an estimated 44,073 people were diagnosed with HIV in 2014 (CDC, 2015b). The geographical distribution of HIV incidence reveals an unequal distribution across U.S. regions. Specifically, those living in the Southeast are more at risk of acquiring HIV compared to those living in other regions of the country.

At the end of 2010, the South accounted for the majority (45%) of the estimated 33,015 new AIDS diagnoses, while the Northeast accounted for 24%, 19% in the West, and 13% in the Midwest (CDC, 2015c). CDC has employed a strategy called "High-Impact Prevention" in response to the variations in HIV distribution (CDC, 2011). This High-Impact Prevention involves "using combinations of scientifically proven, cost-effective, and scalable interventions targeted to the right populations in the right geographic areas". African Americans, Hispanics/Latinos and gay, bisexual, and other men who have sex with men (MSM) are three populations which are target by this strategy. HIV incidence and prevalence disparities have been observed among these specific populations.

Based on population size, Blacks/African Americans experience a HIV incidence that is 7 times higher compared to Whites (CDC, 2016c). In 2014, adult and adolescent

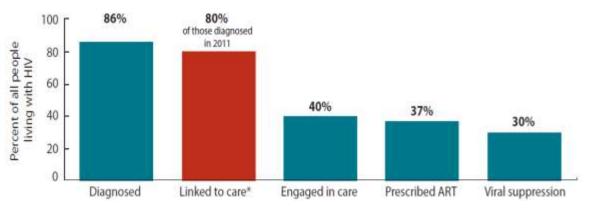
African Americans comprised approximately 44% of all new HIV infections while only accounting for 12% of the U.S. population (CDC, 2015b). Similarly, Hispanics/Latinos represent 17% of the U.S. population but account for almost one quarter (23%) of all estimated new HIV diagnoses (CDC, 2015a). These data elucidate the stark disparities among these minority populations.

Gay, bisexual, and other men who have sex with men (MSM) are another population disproportionately affected by the HIV epidemic (CDC, 2016a). Although MSM represent only 2% of the total U.S. population, they account for 63% of new HIV infections (CDC, 2012a). While gay and bisexual men overall have the highest lifetime risk of HIV diagnosis, that risk varies significantly by race/ethnicity. Specifically, 1 out of every 2 African American MSM and 1 in 4 Hispanic/Latino MSM will be diagnosed with HIV in their lifetime, compared to the 1 in 11 White MSM (CDC, 2016b). Due to the disparities among racial/ethnic and sexual minorities, efforts have been targeted towards prevention through reduction of HIV transmission. These efforts include providing funding to many community-based organizations (CBOs) to improve testing among young MSM, supporting state and local health departments to improve prevention services for MSM, and mobilizing culturally targeted messaging campaigns that encourage HIV awareness.

HIV Care Continuum. Efforts made by CBOs and local, state, and federal agencies are geared to the reduction of HIV transmission. The transmission of HIV is dependent upon an individual's HIV viral load (Cohen et al., 2013; Quinn et al., 2000). Viral suppression can be effectively achieved through antiretroviral therapy (ART) (Cohen et al., 2011). Attainment of viral suppression, or having the status of being

"undetectable", is seen as the ultimate goal for prevention and control of HIV (Cohen et al., 2013). In order for PLWH to attain viral suppression, they need to successfully progress across the HIV Care Continuum stages.

There are 5 stages or steps within this continuum for reaching undetectable viral loads for patients infected with HIV: 1) testing and diagnosis, 2) linkage to care, 3) retention in care, 4) engagement in ART, and 5) achievement of a low viral load at undetectable level (Gardner, McLees, Steiner, del Rio, & Burman, 2011). As seen in Figure 1.1, the first continuum step includes those diagnosed with HIV and in 2011, an estimated 86% of PLWH were diagnosed with HIV (Bradley et al., 2014). Second, linkage is defined by seeing a health care provider within 90 days after receiving a positive HIV diagnosis. Approximately 80% of PLWH diagnosed were linked to care in 2011. Next, engagement/retention in care includes the PLWH (40%) who received and is currently receiving HIV medical care. Being prescribed ART is the fourth step in the continuum and 37% of PLWH are in this step. An estimated 30% of PLWH are in the fifth and final step, which is achieving viral suppression.



Source: CDC. Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV — United States, 2011. MMWR. 2014;63(47):1113-1117.

Figure 1.1. Prevalence-Based HIV Care Continuum among all PLWH, 2011

Timely linkage to and consistent engagement in HIV care and treatment are associated with improved health outcomes (Giordano et al., 2007). However, it is not uncommon for PLWH to not be linked with the appropriate HIV care. In 2011, 80.6% of MSM with diagnosed HIV were linked to care, but only 57.5% were retained in care, 52.9% were prescribed antiretroviral therapy (ART), and 44.6% had achieved viral suppression (CDC, 2012b). Furthermore, there are racial/ethnic disparities among MSM across the care continuum. Black/African American MSM had the lowest linkage to care (71.6%) compared to Hispanic/Latino (80.3%) and White MSM (82.9%) (Singh et al., 2014). Similarly, African American MSM had the lowest retention in care (46.3%) compared to White (52.1%) and Hispanic/Latino MSM. Although all of these racial/ethnic groups have low ART prescription use, fewer African American MSM (47.1%) are in ART compared to their Hispanic/Latino (49.2%) and White (49.6%) counterparts. Further, African American MSM have lower viral suppression (37.0%) than Hispanic/Latino (41.5%) and White MSM (43.9%).

Delays in linkage to medical care are associated with a greater likelihood of progressing to AIDS, which is characterized by a low CD4 cell count. Full engagement in care involves timely treatment with appropriate anti-retroviral medications as well as early detection and management of medical complications (Giordano et al., 2007). Lack of engagement in care has been found to be related to an increased viral load, lower CD4

count, (Berg et al., 2005) and poor survival (Giordano et al., 2007). This also suggests that those not engaged in care are at an increased risk of transmitting HIV to others (Metsch et al., 2008). Despite evidence demonstrating the importance of linkage to and retention in care, HIV care providers report disparities with both linkage and retention of patients (Fleishman et al., 2012; Lamb, El-Sadr, Geng, & Nash, 2012; Rice, Delpech, Chadborn, & Elford, 2011).

NHAS Prevention Efforts. In order to decrease HIV transmission and increase the number of PLWH achieving viral suppression, the Office of National AIDS Policy (ONAP) has developed the National HIV/AIDS Strategy of the United States (NHAS) with the primary goal of reducing the number of people who acquire HIV (ONAP, 2010). Since the first comprehensive NHAS was released in 2010, people and organizations have united together to work towards achieving its vision and goals (ONAP, 2015). In order to facilitate the continued reduction of HIV, the 2015 NHAS update aims to 1) "reduce new HIV infections", 2) "increase access to care and improve outcomes for PLWH", 3) "reduce HIV-related disparities and health inequities", and 4) "achieve a more coordinated national response to the HIV epidemic".

Effective implementation of the NHAS strategies is essential towards improving HIV care continuum outcomes such as achieving viral suppression through ART. (Giordano et al., 2007). After the 2015 update, NHAS altered its linkage to care goal from increasing the number of newly diagnosed persons linked to care within 3 months of diagnosis to linkage within 1 month of diagnosis. Among self-reported HIV-positive MSM in 2014, 98% reported at least one HIV care provider visit; of these men, 82% reported the visit within 3 months of diagnosis and 91% reported visiting a health care

provider for HIV care within the last 6 months (CDC, 2016a). Recent use of ART was reported by 87% of these HIV-positive MSM.

Role of Coping Strategies in the HIV Care Continuum. There is a body of literature that indicates the stress of receiving a diagnosis of and living with HIV has a profound impact on the health outcomes and treatment engagement of PLWH (Cole, 2008; Ironson et al., 2005; Leserman, 2008). Coping is a process that involves both cognitive and behavioral responses to perceived stressors. Recent studies suggest that coping strategies, such as avoidance, denial, and enacting hopelessness, are strongly correlated with faster HIV disease progression (Chida & Vedhara, 2009).

Stress management invokes a process of assessment and adoption of distinct coping strategies to manage specific disease states (Lazarus & Folkman, 1984). With respect to HIV, it is important to recognize the fluidity of disease states among PLWH. HIV disease progression refers to the movement across the three different stages of HIV infection: Acute, Chronic, and AIDS (AIDS.gov, 2015). Acute HIV infection is the initial stage of HIV and develops within a month after a person is exposed. Chronic HIV infection, also known as clinical latency, is the second stage; these people may not display any HIV symptomology but are still able to transmit HIV to others. If left untreated, HIV can progress to AIDS. AIDS is diagnosed when a person's CD4 cell count is below 200 cells/mm3 and, if left untreated, reduces a person's life expectancy drastically. Coping strategies may help PLWH to alter their disease progression, resulting in optimal management of their illness at each particular stage.

#### **Study Purpose and Justification**

Active coping strategies have a strong relationship with positive health indicators, such as higher CD4 count and lower viral load, increased self-efficacy, and greater social support (Mosack et al., 2009; Orban et al., 2010). As MSM are more impacted by HIV than any other group in the U.S., more research attention has focused on examining MSM HIV coping strategies. Previous studies have also identified other strategies employed by MSM (Alvy et al., 2011; Kelly, Bimbi, Izienicki, & Parsons, 2009; Martin & Alessi, 2010; Penedo et al., 2003). For instance, avoidance coping is associated with increased risky sexual behaviors, thereby contributing to a greater likelihood of HIV transmission among MSM (Martin & Alessi, 2010). Less avoidance coping and more utilization of approach-based coping strategies (e.g., planning, seeking social support) have been associated with fewer signs of psychological distress (Penedo et al., 2003).

Although previous studies have established the relationship between stress, coping strategies, and HIV clinical outcomes, there is sparse literature detailing the coping strategies used by PLWH across the care continuum. HIV is associated with immense psychological stress, which greatly impacts behavior and health outcomes.

MSM living with HIV (MSM-LWH) are more susceptible to experiencing emotional disturbances (i.e. anxiety, depression, feelings of helplessness) when compared to their seronegative counterparts and other PLWH (Blaney, Millon, Morgan, Eisdorfer, & Szapocznik, 1990; Thompson, Nanni, & Levine, 1996; Viney, Henry, Walker, & Crooks, 1989).

The utilization of distinct coping responses might account for the differences in care engagement across the care continuum. Therefore, identifying which coping

strategies are most utilized by MSM-LWH could close the gap of racial and sexual identity disparities across the care continuum. Few studies have explored the distinct coping strategies utilized by racial and ethnic minorities, with the exception of religiosity (Foster, Arnold, Rebchook, & Kegeles, 2011; Jeffries et al., 2014). With a lack of depth in the MSM-LWH coping literature, this research attempts to provide insight for future interventions that works toward improving retention in care and adherence to treatment among minority MSM-LWH.

#### **Theoretical Framework**

This study uses the Transactional Model of Stress and Coping, which is a framework that examines the processes of coping with stressful experiences (Figure 1.2). The model defines stressful experiences as "person-environment transactions", where the influence of a stressor is facilitated through one's assessment of the stressor and the resources that can be utilized to address that stressor (Cohen & McKay, 1984; Lazarus &

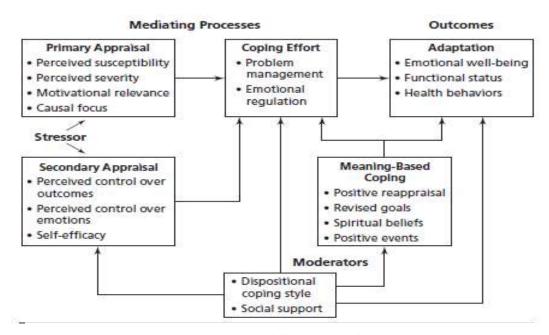


Figure 1.2: Transactional Model of Stress and Coping

Cohen, 1977). In terms of assessing the impact of a stressor, the model describes the initial constructs as two different types of appraisal, primary and secondary (Glanz, Rimer, & Viswanath, 2008).

Primary appraisal is defined as the process of evaluating whether the stressor presents any harm or threat. The two major types of primary appraisal include perception of susceptibility and the perception of severity. While there is an opportunity to perceive a stressful event as a threat, primary appraisals also act to minimize the importance of threats, particularly when the threat is uncertain. This is called "appraisal bias" and has been demonstrated in previous studies (Ditto, Croyle, & Croyle, 1995). For instance, beliefs of invulnerability to developing AIDS among MSM-LWH were associated with reduced distress, enhanced perceived control, active coping, and better overall adjustment (Taylor et al., 1992). Among younger MSM, perceptions of the severity of HIV and AIDS have altered following advances in ART (van der Snoek, de Wit, Mulder, & van der Meijden, 2005). This perceived lesser severity of HIV translates to less perceived need to practice safe sexual behaviors, which is associated with an increased risk of seroconversion.

Secondary appraisal involves a person's capability to change their situation or manage negative emotions associated with the stressor. Secondary appraisal includes one's perception of control, perception of management capability, and self-efficacy. Appraisal impacts coping efforts (e.g., problem management, emotional regulation), which leads to certain health outcomes or changes (i.e. health behaviors, mental well-being, functional status).

Coping efforts, also known as coping strategies, are divided into two distinct categories, problem-focused coping and emotion-focused coping (Lazarus & Folkman, 1984). Problem-focused coping involves utilizing problem management strategies that are aimed at altering the causes and effects of a stressful situation (active coping, planning, problem solving, restraint and information seeking) (Glanz et al., 2008). Emotion-focused coping focuses on adjusting thoughts and feelings about the stressor (i.e. seeking social support, venting, avoidance, self-blame, substance abuse and denial). For example, MSM who identified as "barebackers" (unprotected anal intercourse) were more likely to report drug use and sex under the influence of drugs (Kelly, Bimbi, Izienicki, & Parsons, 2009) and experience self-blame-related coping, and substance abuse coping, which both are emotion-focused coping strategies.

Coping outcomes refer to adaptations to the stressor after the primary and secondary appraisal has taken place, which can include depression, increasing communication with medical providers, or medication adherence (Glanz et al., 2008). This model is useful for describing the effect coping has on managing the physiological and psychological stress of being diagnosed with and the management of HIV. This model also operationalizes key components of the coping process. The explicit incorporation of distinct coping strategies, higher order categories for these strategies (i.e. problem-focused vs. emotion focused), and the model's consideration of evaluative properties in a stress response make this model ideal for the study of HIV related stress and health outcomes.

#### **Research Questions**

The purpose of this research is to conduct a qualitative analysis on the coping behaviors of African American and Hispanic/Latino MSM-LWH. Specifically, this research will be aimed at examining the coping strategies or efforts among the MSM-LWH across the HIV care continuum.

The specific research questions include:

- 1. What are the coping strategies employed by racial/ethnic minority MSM-LWH?
- 2. According to the transactional model of stress and coping, what are the similarities and differences in the coping process of MSM-LWH across the care continuum?

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

This review provides an overview of the impact that stress has on general health outcomes as well as the association between stress, immune functioning, and HIV clinical outcomes. The review also explores the relationships between coping strategies and HIV treatment adherence. Few studies have been conducted on emotion- and problem-focused coping strategies utilized by MSM-LWH across the HIV care continuum. Associations between coping and treatment adherence among MSM-LWH are vastly understudied.

#### The Impact of Stress on Health

Lazarus and Folkman (1984) defined stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." Disease, whether physical or mental, is likely to be appraised as challenging, exhausting, or a threat to one's health. Therefore, disease and its associated events can be considered as stress or stressful events. Stress has been known to exert detrimental physiological and psychological effects upon the human body (Cohen, Janicki-Deverts, & Miller, 2007). In terms of stress caused by a physical disease, the manifestation of stress is usually expressed through the experience of depression or anxiety, which can affect the biological and behavioral aspects associated with disease risk and progression (Cohen, Kessler, & Gordon, 1995). Exposure to chronic stress, which includes disparate events that occur over a long period of time or a single event that has long-term effects, produces even more adverse responses in and changes to the body (Baum, Cohen, & Hall, 1993; Cohen et al., 1995; Flier, Underhill, & McEwen, 1998). Stress on the immune and inflammatory biological

processes of the body can induce the development or acquisition of depression, coronary artery disease, certain cancers, and autoimmune diseases (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002). Therefore, the suppression of immune function due to stress is particularly relevant towards the study of HIV.

## **Stress and HIV Disease Progression**

Due to the advances in ART, survivorship among PLWH has exponentially increased and a paradigm shift towards considering HIV/AIDS a chronic illness followed (Mitchell & Linsk, 2004). Although mortality rates have stabilized through the years, those who find themselves living with HIV perceive the disease as a major source of psychological and physiological stress (Faulstich, 1987).

The stress experienced by PLWH is mostly derived from their disease status, specifically from their individual assessment of their disease (Faulstich, 1987; Morin, Charles, & Malyon, 1984). Multiple studies suggest that the level of perceived stress, as opposed to the nature of the stressor, regulates the strength of the stress response (Glaser & Kiecolt-Glaser, 2005; Maes et al., 1998; Marketon & Glaser, 2008). Depression and anxiety, the two most common psychological illnesses among PLWH, are associated with increased HIV symptomology and accelerated progression to AIDS (Cabaj, 1996; Ickovics et al., 2001). Thus, research that is focused on identifying the linkage between stress and HIV disease progression has been concentrated in utilizing measures that assess for depression and anxiety to assist in assessing perceived stress.

While there have been advancements in clinical research geared toward discovering a cure for HIV, the chronic nature of the disease also leaves PLWH exposed to chronic stress. Chronic stress has been linked with faster disease progression of HIV

(van Eck, Berkhof, Nicolson, & Sulon, 1996; Vedhara, 2005). Among MSM-LWH, the risk of illness progression increased 50% for each additional moderately severe traumatic event; these traumatic events are further associated with a 2.5 times increased risk of developing an AIDS-related clinical condition (J Leserman et al., 2002). The experience of stress has also been found to affect the possibility of PLWH acquiring other viral diseases to which they are particularly vulnerable (Pereira et al., 2003).

A systematic review on the association between stress and the clinical outcomes for PLWH reveals that there have been multiple studies on the associations between stress and HIV clinical outcomes. Through the use of different psychological measures, such as the Center for Epidemiologic Studies Depression Scale (Radloff, 1977), Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) and the collection of biomarkers (i.e. cortisol levels), researchers have been able to identify linkages between stress and different clinical outcomes (e.g., CD4 cell counts, viral load, HIV disease progression, treatment adherence, immune functioning). Multiple studies found that higher levels of stress were negatively associated with CD4 count (Cole et al., 2001; Ellis, 2012; Glover, Garcia-Aracena, Lester, Rice, & Rothram-Borus, 2010; Ironson et al., 2008; McCain & Cella, 1995; Remor, Penedo, Shen, & Schneiderman, 2007). Higher levels of stress also interfere with efforts to increase CD4+ cell counts through medication interventions and are related to a higher viral load (Cole et al., 2001; Ironson et al., 2008). Additionally, cumulative life stress has been found to predict faster disease progression from HIV to AIDS (Leserman, 2008). Higher stress levels also have indirect effects on clinical outcomes; PLWH with high stress levels typically have poor treatment adherence (Bottonari, Roberts, Ciesla, & Hewitt, 2005; L. Delahanty, M. Bogart, & L.

Figler, 2004), which can further the disease progression and contribute to virological failure (Mugavero et al., 2009).

#### Perceived Stress, Stress Management, and Coping

PLWH are susceptible to numerous physical symptoms that have the capacity to unfavorably affect their quality of life, such as fever, fatigue, extensive weight loss, and pneumonia (Cunningham et al., 1998). Findings from past studies imply that HIV disease symptomology can be reduced through the utilization of stress management therapy or stress reduction techniques (Antoni et al., 1991; Lutgendorf et al., 1997). PLWH who utilize stress management strategies experience improved physical health, mental health, and quality of life (Gielen, McDonnell, Wu, O'campo, & Faden, 2001). A further examination on coping will contribute to gaining a better understanding of the common responses to HIV related stressors and developing strategies to increase treatment adherence.

The transactional theory of stress and coping refers to coping as the response, either behavioral or cognitive, to something that is judged or perceived as being stressful (Lazarus & Folkman, 1984). While this definition is the most widely accepted conceptualization of coping, others describe coping as a process that involves the utilization of strategies that seek to either eliminate, reduce, and manage instances of distress or periods of chronic stress (Pearlin & Schooler, 1978). Regardless of which definition is used, it is evident that the discussion of stress is intertwined with understanding coping and its effects on that stress. As it is well established that physiological responses to HIV-related stress are associated with adverse health outcomes, there is an assumption that the behavioral responses, coping strategies, can

also carry negative health outcomes. However, utilization of coping strategies can also yield positive health outcomes for PLWH. One study found that older adults living with and effectively managing their HIV utilized certain meaning-based coping strategies to successfully cope with their status and other related stressors (e.g., treatment of comorbidities, financial stressors due to housing, employment, or purchasing medication) (DeGrezia & Scrandis, 2015). This study found that receiving and providing social support was essential in dealing with their HIV related stress. Further, these MSM-LWH identified spirituality as a means to relieve HIV related stress by sharing the burden with a higher power.

An individual's perceived stress after a positive HIV diagnosis has been associated with certain coping strategies (Pala & Steca, 2015). In a cross-sectional study of 248 HIV patient participants, Pala and Steca (2015) utilized several measures (e.g., Brief Illness Perception Questionnaire (Brief-IPQ) (Broadbent, Petrie, Main, & Weinman, 2006), an adapted 14-item COPE questionnaire (Carver, Scheier, & Weintraub, 1989), and HIV progression biomarkers (i.e. CD4+ cell counts and viral load)). They used these measures to determine associations between different levels of HIV illness perceptions and dysfunctional coping strategies. Findings revealed that patients who had more awareness or belief that HIV had a greater impact on their lives were more likely to use passive coping strategies, which involved a lack of taking action steps to reduce HIV related stressors. Lower perception of HIV illness influence was associated with using more avoidant coping strategies compared to those with higher perception. These PLWH were also more prone to alcohol use and positive reappraising coping.

Previous studies report that coping responses to disease-related stress can also include increased smoking, inconsistent sleeping, poor exercising habits, and reduced adherence to medication regimens, all of which influence disease risk (Cohen et al., 2007). The relationship between stress, coping, and treatment adherence is especially important when focusing on PLWH's progression across the care continuum. Since there is a strong association between HIV related stress and poor immune function, research has placed a spotlight on determining which coping strategies improve or are detrimental to the health outcomes of PLWH.

The literature on coping and HIV can be considered very extensive and heterogeneous due to differences among the measurement tools, outcomes, and conclusions (Moskowitz, Hult, Bussolari, & Acree, 2009). Although this heterogeneity exists, the bulk of literature on coping and HIV has been grounded upon the transactional theory of stress and coping (Lazarus & Folkman, 1984). There are many ways to cope with stress, such as denying one's situation, developing a plan of action, or seeking out social support. While other have grouped the various coping responses into dichotomous theoretical or empirical distinctions like approach versus avoidance (Roth & Cohen, 1986) or active versus passive (Billings & Moos, 1981), the creators of the transactional theory of stress and coping grouped coping strategies into problem-focused versus emotion-focused (Folkman & Lazarus, 1980). Problem-focused coping refers to strategies that focus in altering the source of the stress (Carver et al., 1989). Emotion-focused coping refers to strategies that minimize or manage the stressful event.

Although there is abundant literature on HIV coping research, few studies have compared the problem- vs emotion- focused coping dichotomy (DeGenova, Patton,

Jurich, & MacDermid, 1994; Gore-Felton et al., 2002; Pakenham & Rinaldis, 2001). In a study assessing coping styles, depression, and physical health among 85 PLWH, DeGenova et al (1994) found a significant association between emotion-focused coping and depression compared to problem-focused coping. These findings suggested that PLWH who utilized emotion-focused coping strategies were more likely to experience depressive symptoms. Depression has been linked to attrition across the HIV continuum steps (Pence, O'Donnell, & Gaynes, 2012). This suggests that certain coping strategies have a positive or detrimental impact on engagement across the HIV care continuum. Pekenham & Rinaldis (2001) reported an association between three emotion-focused strategies (self-blame, wishful thinking, and avoidance) and high levels of stress and depression. Gore-Felton et al (2002) reported that emotion-focused coping was positively associated with risky sexual behaviors, such as unprotected sex, which has implications for HIV transmission to others. When compared to problem-focused coping, no association existed. Although these few studies cannot provide substantive implications for the HIV care continuum, they do provide enlightenment on the different outcomes and risks associated with emotion- and problem-focused coping.

#### **Coping and Treatment Adherence among MSM-LWH**

Although the sparse literature on emotion- and problem-focused coping among PLWH cannot provide insight for coping across the HIV care continuum, one study examined treatment adherence and coping characteristics among MSM (Halkitis, Parsons, Wolitski, & Remien, 2003). Analyzing data taken from the Seropositive Urban Men's Study (SUMS), a formative study of 456 MSM-LWH from New York City and Los Angeles, Halkitis and colleagues found that avoidant coping and increased alcohol

abuse, subcategories of emotion-focused coping, were related to days where treatment adherence was interrupted.

While literature establishes the linkage between high stress levels and poor HIV clinical outcomes, it does not establish a concrete association between stress and coping. In addition to the lack of consensus on effective coping strategies to mitigate HIV related stress, there is no substantive evidence linking specific coping strategies utilized by MSM-LWH across the care continuum. Therefore, the focus of this study will be to identify the coping strategies utilized by African American and Hispanic/Latino MSM-LWH across the care continuum.

## Specific Research Questions include:

- 1. What are the coping strategies employed by racial/ethnic minority MSM-LWH?
- 2. According to the transactional model of stress and coping, what are the similarities and differences in the coping process of MSM-LWH across the care continuum?

#### **Chapter 3: Methods**

Methods for this study include a secondary qualitative analysis of an existing data set. The original data were collected by Research Support Services (RSS) and two additional partners, Emory University and IMPAQ International LLC (IMPAQ), under a contract with the CDC's Division of HIV/AIDS Prevention (DHAP), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP). The primary goal of the original study was to explore facilitators and barriers related to linkage to and engagement in HIV care among racial/ethnic minority MSM-LWH. Another goal of the original study was to identify possible interventions that could increase access to care, improve health outcomes, and reduce HIV-related disparities among MSM-LWH. The original study was conducted in five metropolitan areas in the United States – Atlanta, Georgia; Washington, District of Columbia; Baltimore, Maryland; Los Angeles, California; Chicago, Illinois. These sites were selected because have high HIV/AIDS incidence and prevalence rates among Black/African American and Hispanic/Latino MSM.

The purpose of this secondary analysis is to explore coping strategies utilized by racial/ethnic minority MSM-LWH to respond to their HIV illness, care, and treatment. Secondary analyses of qualitative data sets is an established approach to yield additional insights (Fielding & Fielding, 2000; Gladstone, Volpe, & Boydell, 2007).

# **Study Population**

The study population consisted of Black/African-American and Hispanic/Latino MSM-LWH. Eligible respondents were male at birth and living with HIV. Participants also had to satisfy additional eligibility criteria (18 years or older, English or Spanish

speaker). Eligible MSM could fall within any stage of the HIV care continuum, which included those who have been linked to care and have begun treatment with ART (care engaged), those who have been linked to care and have disengaged (care inconsistent), or those who have refused HIV treatment with ART (care detached). Eligibility criteria for this study also included individuals who were identified as HIV-discordant partners of a PLWH, meaning they have never received a positive diagnosis; these partners had to identify as MSM, be over 18 years old, be able to converse easily in English or Spanish, and be in an ongoing sexual relationship with a PLWH.

## **Participant Recruitment**

In each city, local healthcare providers, staff at HIV treatment centers, and staff at CBOs that serve the target populations helped recruit eligible participants in the original study. Providers and staff distributed advertisement flyers at these venues. Additional advertisements were placed in publications, which targeted the LGBTQ and PLWH community. Interested participants contacted the study team via email or a toll-free number where a study staff member screened the potential participants to assess eligibility. During the screening process, the recruiters kept the contact documents and screener responses separate to ensure that the potential participants' personal information would not be linked to the study. At the end of the screening, participants who met all the eligibility criteria were provided further details, including the purpose of the study, the participant's role in the study, study requirements and time commitment, and any other questions or concerns. The study participant then identified a convenient time and place for the in-depth interview to be conducted accordingly.

Screening for identification of HIV-discordant partners was conducted during the screening of eligible MSM-LWH. The screener clarified that eligible partners must be aware of their partners' HIV-positive status. A study staff member contacted the HIV-discordant partner with the contact number provided by the PLWH and proceeded with a subsequent eligibility screening. Overall, the screening process usually took approximately five minutes to complete.

#### **Informed Consent**

Prior to beginning the face-to-face interview, participants were asked to sign an informed consent form that included a description of the study, risks and benefits of participation, duration of participation, research contact persons including the chair of the IRB, the voluntary nature of participation, and the right to withdraw without penalty. During the informed consent process, the interviewer went over the informed consent form aloud as well as gave the participant time to read the form on his own. The interviewers read the form to any participant who requested it. Participants were also able to ask any additional clarifying questions prior to signing the consent document. During the consent process and before the start of the interviews, participants were reminded that all answers are voluntary, they could refrain from responding to any question, and they would receive \$40 for participation regardless of response frequency and full completion of the interview questions. If the PLWH chose to participate and signed the consent form, then they were given a copy of the form for their records while the study interviewer retained the other copy for study records. In order to be fully prepared for any strong emotional and distressed responses that might have emerged from answering the interview guide questions, the interviewers were equipped with cityspecific lists of HIV and mental health care providers.

# **Study Sample**

The study sample consisted of historically marginalized PLWH who were Black/African-American MSM (n=53) and/or Hispanic/Latino MSM (n=36). Furthermore, 15 HIV-discordant MSM partners of respondents were selected. Because young (18-30 years) and lower socioeconomic status (SES) MSM have not been adequately represented in other HIV care continuum behavioral research studies, these attributes were tracked to ensure representation and appropriate distribution throughout all study subgroups. While there were a total of 99 participants, this study will only analyze information from the 84 MSM-LWH participants. Because this research focuses on being within the HIV care continuum, data from those who were not living with HIV were excluded from the secondary analysis.

#### **Study Instruments**

The original study team developed two separate interviewer guides for the MSM-LWH and the subsample of their HIV-discordant partners. The beginning of the interviewer guide included a close-ended quantitative portion that asked for demographic, SES, and household information. These items were asked for both MSM-LWH and HIV-discordant partner samples. The open-ended interview guide included questions about HIV diagnosis and testing history, social support, experience with treatment, and perceived barriers to HIV care and treatment adherence. This method of using a semi-structured interview guide allowed study participants to provide detailed responses and discuss other concerns. Two questionnaires were also developed to ensure that the open-

ended items were pertinent to issues specific to MSM-LWH and HIV-discordant partner participants and to inform the development of culturally appropriate, tailored interventions for MSM-LWH from various socioeconomic categories and geographic locations to reduce barriers related with engagement and retention in HIV care and treatment.

**Survey Measures.** All study participants also completed brief sociodemographic questionnaires at the beginning of the study visit. The questionnaire was incorporated into the interview guide for subsequent quantitative analyses. The questionnaires consisted of items related to demographics, including household living arrangements, employment, and insurance status among other standard demographic questions (e.g., age and racial/ethnic status).

#### **Data Collection and Management**

All interviews were digitally recorded with the consent of the participant. Two recording devices were used to ensure no data was lost to a poor recording or human error. When the interview was completed, the interviewer checked the quality of the recordings. After every interview, each tape was transcribed for data analyses. Interviews that were conducted in Spanish were transcribed into English by RSS. Transcripts excluded personal identifying information (PII) including names, locations, and other characteristics that could reveal the identity of interviewees, their partners, their providers, and clinics and care locations. All materials, including recording devices, consent forms, and interview guides, were then transferred to locked cabinets in secure locations. All PII from the screening process was maintained on paper and kept in

separate locked cabinets from other data. All transcripts, without PII, were kept on encrypted key drives.

# **Secondary Data Analysis**

In the original study, all transcripts were structurally coded using NVivo 10.0. Codes were initially developed from their corresponding questions on the interview guide. Team members reviewed transcripts to further develop codes and categories and to identify emerging themes. In order to examine the coping strategies employed by the study participants for the secondary data analysis, the transcripts were also coded with Nvivo 11.0 with a new codebook.

Codebook Development. The development of the codebook was driven by a deductive process. Specifically, codes and code definitions were based on the constructs from the transactional model of stress and coping (e.g., coping efforts, meaning based coping, primary appraisal, secondary appraisal). However, coping efforts involved many different problem-focused and emotion-focused coping strategies. In order to capture a comprehensive understanding of the coping strategies used by study participants, this research study developed a codebook template that utilized two well-established quantitative instruments to assist in defining the coping strategies. Dimensions, subscales, and items from these two instruments, COPE inventory and the Brief COPE scale, were used to identify codes and reinforce code definitions. The COPE inventory is a questionnaire that aims to assess the different ways people respond to stress and includes a multitude of coping dimensions (4 items per dimension) (Carver et al., 1989). The Brief COPE scale, adapted from the COPE inventory, is designed to assess a comprehensive range of coping responses among adults for all diseases (Carver, 1997; Carver et al.,

1989). It contains 28 items and is rated by the four-point Likert scale, ranging from "I haven't been doing this at all" (one) to "I have been doing this a lot" (four). In total, there are 14 dimensions in this scale with two items per dimension. These dimensions include self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame.

The reliability and validity of these tools justify their utility for codebook development. Past studies that have attempted to establish the reliability and validity of the scales demonstrated high Cronbach's alpha values for domains such as religion ( $\alpha$ =0.82) and substance use ( $\alpha$ =0.90) (Carver, 1997). Other domains also had acceptable Cronbach's alpha values, such as active coping ( $\alpha$ =0.68), planning ( $\alpha$ =0.73), positive reframing ( $\alpha$ =0.64), acceptance ( $\alpha$ =0.57), humor ( $\alpha$ =0.73), emotional support ( $\alpha$ =0.71), instrumental support ( $\alpha$ =0.64), self-distraction ( $\alpha$ =0.71), denial ( $\alpha$ =0.54), venting ( $\alpha$ =0.50), behavioral disengagement ( $\alpha$ =0.65), and self-blame ( $\alpha$ =0.69). Because both measures assess a comprehensive list of different coping strategies and most of the subscales demonstrate acceptable reliability, the items or survey questions were utilized to develop strong code definitions.

**Development of Code Definitions**. These definitions were created with the use of the items from their corresponding coping strategy subscale. For example, in the Brief COPE scale, planning as a coping strategy included the two following items: "I've been trying to come up with a strategy about what to do" and "I've been thinking hard about what steps to take". Language from these items were adapted to relate to HIV and the study population. After initially coding 9 interviews, the code definitions were adjusted

again to include other dimensions of the code not fully captured through the adaptation of the quantitative measures. Therefore, the final definition of the planning code included the following phrases: "descriptions or statements of thinking about dealing with the problem", "it also includes discussion of and coming up with action strategies to best handle their situation", and "it includes statements of plans to start taking action steps to seek care". After development of a uniform codebook, the process of open coding was conducted for the rest of the transcripts. Open coding refers to identifying and labeling significant units of text, which might be a word, phrase, sentence, or larger section of text (Burnard, 1991). Through this process, the coping strategy codes that were initially in the deductive codebook template but hadn't emerged from any of the transcripts were eliminated from the final codebook. The final codebook can be found in Appendices A and B. During the open coding process, transcripts were reviewed to determine if there were other emerging thematic codes that related to coping and the transactional model of stress and coping.

Content Analysis. During the open coding process, participant discussion of utilization of a coping strategy was tracked on an Excel file. After coding was completed for each transcript, the NVivo software was used to identify specific codes in that same transcript. The codes that referred to problem- and emotion-focused coping strategies were then noted on the Excel file. The entire transcript was reviewed for identification of utilization of specific coping strategies. Therefore, if evidence for a specific coping strategy appeared in a transcript and was coded one or more times, then that coding strategy would be considered as being utilized by the participant. The quantity of how many times the code emerges in the transcript was not captured. Additionally, the

temporal context of coping strategy utilization was also not considered. Subsequent content analysis was conducted using the finalized codes to examine the utilization of coping strategies by care continuum group. Demographic data from NVivo and code count data tracked in Excel was imported into SPSS for descriptive analyses, which included frequencies, percentages, and cross tabulation of variables.

Analysis by Care Continuum Group. In order to determine similarities and differences among MSM-LWH across the HIV care continuum, a thematic analysis of coping strategies utilized by study participants was conducted. The development of HIV care continuum typologies assisted in the examination of this study's second research question. This study refers to three typologies related to three continuum stages: care engaged, care inconsistent, and care detached. These care continuum stages can also be considered as coping outcomes within the scope of this theoretical model. In this study, MSM-LWH who were care engaged were considered to be in active care (having attended 2 or more provider visits in past year, routinely obtained CD4/VL levels, being virally suppressed or ARV adherent). Care inconsistent MSM-LWH had experience with some care and treatment (having attended at least 1 provider visit in past year, obtained at least 1 follow-up CD4/VL test post-diagnosis, VL fluctuation, expressed inconsistent or no ARV use). Care detached MSM-LWH were characterized by no routine care (no reports of routine provider visits, no CD4/VL tests since diagnosis, no ARV use among these men).

# **Statistical Analyses**

Statistical analyses were performed using SPSS version 22.0 for Windows (IBM SPSS Inc., Chicago, IL, USA). Descriptive statistics were calculated for all variables,

including means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Fisher's exact tests were used when at least one expected cell count was less than 5. Chi-square tests of independence were used to assess significant differences in sociodemographic variables between the subgroups.

Specifically, chi-square analyses were conducted to quantify variations in coping strategies between care continuum groups within the sample according to race and ethnicity and city of residence. All statistical tests were evaluated at a significance level of 0.05.

#### **Chapter 4: Results**

A total of 84 MSM-LWH participated in the original study. Data from all of these respondents were included in this secondary data analysis. Table 4.1 presents sociodemographic characteristics associated with our sample. The majority of the participants were ≥36 years old (n=60, 71.4%). Within this study, there was a relatively even distribution of the participant's city of residence: Atlanta (n=24, 28.6%), Baltimore or Washington DC (n=17, 20.2%), Chicago (n=22, 26.2%) and Los Angeles (n=21, 25.0%). The majority of participants identified as gay (n=57; 67.9%) and as Black or African American (n=52; 61.9%).

This study utilized three typologies representing the care continuum stages: care engaged, care inconsistent, and care detached. Care engaged men (n=42, 50%) were considered to be in active care, which included: having attended 2 or more provider visits in past year, routinely obtaining CD4/VL levels, and being virally suppressed or ARV adherent. Care inconsistent men (n=19, 22.6%) were those having experience with some care, which included attending at least 1 provider visit in the past year, obtaining at least 1 follow-up CD4/VL test post-diagnosis, VL fluctuation, and expressing inconsistent or no ARV use. Care detached men (n=23, 27.4%) described no routine care, with no reports of routine provider visits, CD4/VL tests since diagnosis, and ARV use among these men.

Table 4.1: Sample Characteristics for MSM-LWH in 5 cities, 2014 (n=84)

	Frequency (%)
City	
Atlanta	24 (28.6%)
Washington DC or Baltimore	17 (20.2%)
Chicago	22 (26.2%)
Los Angeles	21 (25.0%)
Sexual Identity	
Gay	57 (67.9%)
Straight (that is, not gay)	1 (1.2%)
.Bisexual	17 (20.2%)
Something else or Don't know / Questioning	9 (10.7%)
Age	
18-25	7 (8.3%)
26-35	17 (20.2%)
36 and over	60 (71.4%)
Ethnicity	
Hispanic / Latino or Spanish Origin	36 (42.9%)
Not Hispanic / Latino or Spanish Origin	46 (54.8%)
Don't know or Refused	2 (2.4%)
Race†	
Black or African American Only	52 (61.9%)
White Only	14 (16.7%)
American Indian or Alaska Native Only	2 (2.4%)
More Than One Race	1 (1.2%)
Other - Hispanic Only	10 (11.9%)
Other Only	5 (6.0%)
Continuum of HIV Care	
Group 1 (Care-Engaged)	42 (50.0%)
Group 2 (Care-Inconsistent)	19 (22.6%)
Group 3 (Care-Detached)	23 (27.4%)

<sup>†</sup> Five participants indicated "Pacific Islander" as race identification, but were of Caribbean origin. These participant's race has been coded according to their other race responses.

The purpose of this study is to identify the coping strategies utilized by African American and Hispanic/Latino MSM-LWH across the care continuum. Analysis was dependent on the distinctions among all of the different coping strategies related to the transactional model of stress and coping. Problem-focused coping refers to strategies that are geared toward altering the source of the stress, which includes active coping,

planning, restraint, seeking instrumental support, and self-distraction. Active coping is the process of taking active steps to attempt to remove the stressor or restructure its effects (Carver, Scheier, & Weintraub, 1989). Planning is thinking about how to best handle a stressor, which involves the action strategies of thinking about what steps to take and how best to cope with the problem. Restraint coping involves waiting until there is an appropriate opportunity to act, or holding oneself back and not acting too early. Seeking instrumental support includes looking for advice, help, or information. Self-distraction is defined as using behaviors such as watching television, exercising, reading, or engaging in other pleasurable activities to distract oneself from a stressor.

Emotion-focused coping refers to strategies that minimize or manage the stressful event: acceptance, behavioral disengagement, denial, positive reframing, religious coping, seeking emotional support, substance abuse, self-blame, and venting. Acceptance is when the individual accepts the reality of a stressful situation. Behavioral disengagement refers to giving up any attempt to address the stressor. Denial involves the refusal to believe that the stressor exists. Positive reframing is reconsidering stressful events in a positive light. Religious coping involves turning to religion in times of stressful events. Seeking emotional support is the seeking out compassion or sympathy from others. Coping with substance use means using alcohol or drugs to reduce distress. Self-blaming involves blaming oneself for the stressor. Venting is the external expression of emotions, usually in the company of friends or family.

After running chi-square analyses on all of the above mentioned coping strategies, there were distinct variations in coping strategies across the three defined care continuum groups (Table 4.2). Care engaged MSM-LWH primarily utilized problem-focused coping

strategies, including (> 50%) active coping (n=34, 81.0%), planning (n=26, 61.9%) and seeking instrumental support (n=22, 52.4%). In terms of emotion-focused coping, these men utilized the strategy of seeking out emotional support (n=35, 83.3%). Care detached MSM-LWH predominantly utilized emotion-focused coping strategies, including substance abuse (n=12, 52.2%) and seeking out emotional support (n=16, 69.6%). In terms of problem-focused coping, these men utilized restraint coping (n=15, 65.2%). Care inconsistent MSM-LWH utilized both problem-focused coping strategies, including active coping (n=12, 63.2%) and seeking instrumental support (n=10, 52.6%), and emotion-focused coping strategies, including seeking emotional support (n=13, 68.0%) and substance abuse (n=10, 52.6%).

As stated earlier, separate chi-square tests of independence were performed to examine differences in coping strategy utilization between care continuum groups among these diverse MSM-LWH (Table 4.2). Several coping strategies presented statistically significant utilization rates among care continuum groups, including active coping ( $\chi$ 2= 21.908; df=2; p=<0.001), planning ( $\chi$ 2= 18.403; p<0.001), restraint ( $\chi$ 2= 11.486; p<0.003), denial ( $\chi$ 2= 6.788; p=0.028), and self-blame ( $\chi$ 2= 5.222; p<0.036). The other identified coping strategies did not differ significantly between care continuum groups.

Additionally, Chi-square tests were conducted to examine differences in coping strategy utilization between, race/ethnicity and city. Race/ethnicity was stratified into three categories: black (non-Hispanic); Hispanic/Latino; other. The city locations were stratified into the following: Atlanta; Baltimore/Washington DC; Chicago; Los Angeles. With the exception of venting ( $\chi$ 2= 9.011; p=0.024), other coping strategies did not differ significantly (p> 0.05) between different racial/ethnic groups and there were no

significant differences between city locations. These results suggests that race/ethnicity and city are not likely to be major sources of confounding for the discovered associations between continuum group and coping strategies. Hence, differences in coping strategy use between cities and race/ethnicities are unlikely to explain a significant portion of the differences between continuum groups.

Table 4.2: Coping Strategies among MSM-LWH across HIV Continuum Groups

Coping Strategy	Care- Care- Care- Chi-square			
	<b>Engaged</b>	Inconsistent	Detached	Test
	(n=42),	(n=19),	(n=23),	p-value <sup>a</sup>
Duckley Facused Coning	n (%)	n (%)	n (%)	
<b>Problem-Focused Coping</b>				
Active Coping	34 (81.0)	12 (63.2)	5 (21.7)	<0.001***
Planning	26 (61.9)	8 (42.1)	2 (8.7)	<0.001***
Restraint Coping	11 (26.2)	4 (21.1)	15 (65.2)	0.003**
Seeking Instrumental Support	22 (52.4)	10 (52.6)	7 (30.4)	0.196
Self-distraction	1 (2.4)	0 (0.0)	3 (13.0)	0.118
<b>Emotion-Focused Coping</b>				
Acceptance	12 (28.6)	3 (15.8)	5 (21.7)	0.599
Behavioral Disengagement	12 (28.6)	5 (26.3)	8 (34.8)	0.813
Denial	15 (35.7)	1 (5.3)	5 (21.7)	0.028*
Positive Reframing	1 (2.4)	3 (15.8)	2 (8.7)	0.109
Religious Coping	6 (14.3)	7 (36.8)	4 (17.4)	0.131
Seeking Emotional Support	35 (83.3)	13 (68.4)	16 (69.6)	0.306
Self-blame	0 (0.0)	1 (5.3)	3 (13.0)	0.036*
Substance Abuse	14 (33.3)	10 (52.6)	12 (52.2)	0.211
Venting	0 (0.0)	0 (0.0)	1 (4.3)	0.500

<sup>&</sup>lt;sup>a</sup> Chi-square test for difference in rates between continuum groups. Fisher's exact test used when at least one expected cell count was less than 5.

<sup>\*</sup> p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001

## Care Engaged MSM-LWH

With utilization rates over 50% (Table 4.2), care engaged MSM-LWH were able readily able to detail their experiences in using active coping, planning, seeking instrumental and emotional coping responses to the HIV related stress by discussing how these coping strategies enabled engagement in HIV care. However, before employing these strategies, care engaged men underwent an evaluation process which had great influence on their decision to respond to stress with mostly problem-focused coping strategies.

**Primary Appraisal.** Primary appraisal is defined as the process of evaluating whether HIV presents any harm or threat to one's health status. After receiving their diagnosis, some of these men perceived a high threat and immediately sought out care and treatment.

I was feeling some, like um, side effects (HIV symptoms) and I decided to go to the doctor and I make a test and I became HIV positive and I start taking in that time a drug called AZT and going you know, to the general doctor. – Hispanic, age 51

Others responded to their diagnosis through substance abuse or denial, which resulted in a low perception of threat and served as a barrier to care. However, acceptance emerged after the threat level increased (i.e. severe HIV-related symptomology, poor lab results). As stated earlier, to address this new perception of greater susceptibility, they responded by utilizing problem-focused coping strategies.

When I got infected with HIV it was big news and really bad news and I didn't... I didn't want—I just wanna close my eyes and don't pay attention to it so I think that will have—it happened like four years and then I got sick. And I got cancer, yeah. And then so, and my T-cells were already, uh low that I couldn't, I couldn't

get the um, chemo because of the T-cells were that low. So, that was my lesson right there. So, from that time I started taking care of me, I got cure of the cancer and since that time that I took care of me and I start taking my meds, everything. – Hispanic, age 43

Active Coping. Active coping, or the process of taking tangible steps in an attempt to eliminate the stressor or to alter its effects, was one of the most cited problem-focused strategies utilized by care engaged MSM-LWH. It primarily presented in two ways: 1) the initiation to an ARV regimen and 2) the maintenance of care. Initiation of ARV therapy was usually decided upon based on the influence of their health status, provider opinions, and other people in their social network.

I've been married, the conversation has come up about me receiving treatment for it, so this week I'm actually supposed to go to the doctor and give him a date so when to start the medication and treatment. – African American, age 32

Maintenance of care included consistent appointment attendance and contact with providers for reassurance of their health status, which reduced their stress.

Well, my HIV treatment would be, I see my doctor every four months, I take my medicines regularly. If I'm ready to run out, I have a relationship with the pharmacy that they will call and say, you need refills or so forth, and I will have them deliver it to me. If I feel something is happening in my body, I will make contact with the doctor or I have a nurse-practitioner really, and to go to and see, have it checked out. — African American, age 58

Active coping also involved having regular follow up lab tests to remain aware of and maintain their current health status.

Every three to four months usually have them uh, go in and have your lab done a week before your appointment. –African American, age 56

All active coping activities greatly contributed to their continuum status by effectively facilitating their continued engagement in care.

**Planning.** Planning, another problem-focused strategy used frequently by this group, reinforced the active steps taken to address their HIV diagnosis. Some men developed specific tactics that helped them stay on track with their treatment, such as developing care plans. One participant discussed what he actually wrote down on a sheet of paper:

Um, it's just the follow up appointments, the follow up appointments uh, the blood work, um, you know and then all the you know all of the other stuff you know, because a lot times you know like I suffer with uh, with uh you know high blood pressure, um cholesterol so it's just all of that stuff, you know, it's just part of the treatment plan, you know keeping all of that stuff under control. — African American, age 56

Others cited that taking pills at specific times throughout the day helped with ARV adherence.

Yeah. I mean, I take them at bedtime, but the thing is that it depends on when I go to bed. – Hispanic/Latino, age 35

Setting up visual cues (e.g, calendars, location of pill bottles) as reminders also facilitated their retention in care and helped with navigating around individual and structural barriers (e.g., poor memory, transportation).

Yeah I have, like I said that board that I have in the house, I have to also call in my medication because they mail it to me because of transportation issues. So a lot of my medication has to be mailed out so I have to mark on the calendar what days/time to call in you know. I call in like five days before the medication actually is going to run out because they have to mail it and I have to sign for it. – African American, age 48

These cues further served as tools to avoid missing medications by notifying the patient of impending prescription refills.

As I was saying, the pill box, that really helps remind me of if I did take it or did not take it. Then, making sure that I have, when I get low, that I call it in, or else now I have it where they call me, so I have a relationship with the pharmacy — computerized, so they'll call and say that you need to have it, so that's good. I can either go pick it up or have it delivered, so I switched pharmacies also. One time I went to another pharmacy and it was always, you have to wait sometimes two or three hours for refills. Now, it's about a half an hour wait if you go to pick it up, or it can be delivered to you.

— African American, age 58

Finally, use of technology (e.g., programming cell phone reminders) facilitated ARV and appointment adherence.

Seeking Instrumental Support. Help seeking was another common practice among MSM in this group, which facilitated movement across the care continuum. Care engaged MSM-LWH were more open to seeking out advice from other individuals compared to MSM-LWH in the other care groups. Many sought out instrumental support, from partners, family, and friends, during the disclosure process. Their MSM-LWH peers were another source of HIV-related support, by stressing the importance of attending appointments and frequent testing on HIV clinical outcomes (i.e. CD4 cell counts, viral load), and even providing tangible resources to assist with linkage into care.

Yes, very supportive. They told me that there's a lot of places that I can go and places I can be treated if I need to take medication, places where I can go that's helpful towards that disease. – African American, age 45

Care engaged men were also more inclined to discuss the way in which their providers gave them support and how they would seek advice from them.

Now, I have one of the greatest doctors. I see him now every three months...he makes sure I take that [medication] regularly. If I don't, he knows because stuff starts to go crazy. So, I make sure I take it every day. He's very persistent with that... Do not, his thing is stressed, do not miss a dose...And I've seen since I haven't missed. I haven't been missing...

- African American, 52

Seeking Emotional Support. Similar to seeking instrumental support, many of the men sought out emotional support from friends, family members, partners, professionals, and support groups. Discussions of seeking emotional support usually emerged when the men were elaborating on their experiences with HIV disclosure and most of these men were able to gain compassion and empathy from people in their social network.

Well a lot of my family knows. We don't- they don't have a problem with it. Friends, I go to support group that has people that are HIV/substance abuse and stuff like that on Thursdays and we try to kind of like you know guide the ones that are not because I'm a little bit more self-reliant than they are now... -African American, 52

Additionally, men in this group also alluded to their disclosure being a precautionary measure if their health became compromised. They wanted their loved ones to hold decision-making responsibilities for their health if they were otherwise incapacitated.

Actually pretty well, actually pretty well because she [ex-wife] had a boyfriend that died from it after we were divorced so she kind of was like ok well, you know. We are still close and I had elected that if anything happen to me she would be the one that handles anything for me, so I thought she needed to know. – African American, age 48

**Secondary Appraisal.** All of these coping strategies utilized, among this group, were dependent on their self-efficacy. Men who demonstrated high self-efficacy cited the sentiment "I am in control". They stressed the importance of staying in treatment. They

were also more concerned with their lab values and confirming their health status through a provider.

I have control. It does not control me so-today I'm a better person from, I'm a better person. I can't compare myself to any other people because I don't know anyone else... Since I've been diagnosed I was stuck on that numbers, numbers, numbers, numbers, numbers, you got to get these numbers right, you got to get these numbers- and I've met people who has low numbers, I've met people who have high numbers and it was a concern of mine to have high numbers. I'm talking about CD4... to get my CD4 higher than it is. It was a big thing, but I'm undetected for my viral load.

— African American, age 53

Active coping and implementation of planning strategies to stay on an ARV regimen also supported their belief in self-management and their high self-efficacy towards their care.

Figure 4.1 depicts the typical process of coping among care engaged MSM-LWH as it

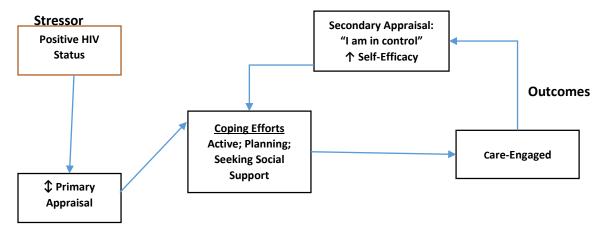


Figure 4.1 Model of Care Engaged MSM-LWH

relates to the transactional model of stress and coping.

### **Care Inconsistent MSM-LWH**

Care inconsistent MSM-LWH utilized both problem-focused coping strategies (active coping and seeking instrumental support) and emotion-focused coping strategies (seeking emotional support and substance abuse) (Table 4.2). This variation of employed coping strategies is mainly attributable to the MSM-LWH appraising their stress in different ways.

**Primary Appraisal.** Care inconsistent men typically perceived a higher level of harm from HIV. This is usually due to a previous negative experience with a compromised immune system and receiving concerning lab results.

Yeah. You know, when I take my meds, it's very important because it saved my life because my T cell go up... My viral loads go down and I'm health. I stop take medication, the viral loads go up, up, up, and then destroy my body.

– Hispanic, age 59

These negative experiences did not always come in the form of assessment of personal harm. However, they always increased awareness of their susceptibility and acted as an impetus to active coping.

Until my partner passed away 5 years ago, it was a wake-up call to me, and now I live life to the fullest... I get a paper cut, I'm gonna go to the doctor right away. I don't play with that no more because I see what life's really about. I took it for granted, and he was a wake-up call for me. It's sad to say, but it takes things like that for you to really realize... - Hispanic, age 55

Active Coping. Active coping was usually expressed when describing their intention to stay in treatment. MSM-LWH in this group were usually back on treatment from a previous stint of receiving care. Similar to those that were care-engaged, there were men who discussed the fact that they have decided to make plans to take ARV medication to stay healthy. In order words, they have acknowledged that ARV treatment

is associated with better health outcomes and necessary to reduce HIV's threat to their lives. Justification for using this coping strategy was extremely driven by results after experiencing a primary appraisal process.

I wouldn't say I have a plan (laughs) I just plan on taking my meds as I should. And live. That's my treatment and care. I do go to the doctor, I don't go as I should but I make sure that I do things that keep me healthy that I know is common sense. I try to eat right, try to exercise, try to have protected sex because I do know that there's other things I could still get that could eventually hurt me. So, that's my plan just to take my medicine and, and live. —African American, 26

Seeking Instrumental Support. Taking active steps to address their HIV status was also facilitated by receiving instrumental support. Unlike care engaged men, MSM-LWH in this group mainly sought out advice and information from other peers living with HIV. One participant stated that he sought out support from a close friend because he trusted his friend's knowledge on HIV.

At that time, just my friend, that one... Because he knew a lot, how to advise me, and he had...time. –Hispanic, 33

Seeking Emotional Support. While men in this group sought advice from their peers, they were able to seek emotional support from other members in their social network. Family members were often a source of support. These men predominately associated instances of empathy and compassion with being supportive, which included others' concern for their health or the men acknowledging that they are cared for.

My brother and sister give me 100 percent support, particularly my sister. We have a great relationship. She is always asking how I'm doing, tries not to, you know, do—for me not to get too upset or nervous about anything because of my health. She worries about my stress. It's a very negative load if you are HIV positive and she knows that. — Hispanic, age 50

Substance Abuse. Although there were some men that were taking productive measures towards viral suppression, others revealed they were still struggling with substance abuse issues. Their continued addiction was cited as a significant barrier to staying in care and treatment. For example, frequent alcohol use was associated with memory loss, which negatively impacted their consistency on an ARV regimen.

Additionally, there was great apprehension with mixing ARV medications with other drugs. The importance of their substance abuse weighed more heavily compared to staying in care and treatment.

But lately, since I've been drinking, like last night I was drinking and I drank like half a bottle of wine... when I went to bed I remembered—I remembered about the pill, but I didn't take it. I didn't feel [that it was okay to take it] with the alcohol in my stomach, no, no, no. So, that's a reason why I often don't take them.

– Hispanic, age 43

**Secondary Appraisal**. Giving up or turning to substance abuse can lead to negative HIV clinical outcomes. Similar to care engaged men, these negative experiences facilitated medication onboarding amongst care inconsistent men to retake control of their health.

Yeah so once I-I stopped taking my meds and so forth my viral load went to 68,000 and my CD4 was like at 5-somehting and I said no. I've got to get back on my meds. - African American, age 50

Being "in control" of their health enables the utilization of effective coping strategies (i.e. active coping and seeking social support). However, there were also some men who were not consistent with the ARV regimen due to feeling healthy and not seeing a change in their health. They struggled with consistency due to being under the assumption that their

bodies were successfully fighting the infection on its own, which would reinforce utilization of ineffective coping strategies (i.e. substance abuse).

I'm always on and off on my medicine... once they tell me that I'm healthy, that I'm undetectable, then I always get it in my mind, well, if I'm healthy and undetectable, then that's even better, so I don't have to take so and so days of medicine. – Hispanic, age 27

Figure 4.2 depicts the typical process of coping among care inconsistent MSM-LWH as it relates to the transactional model of stress and coping.

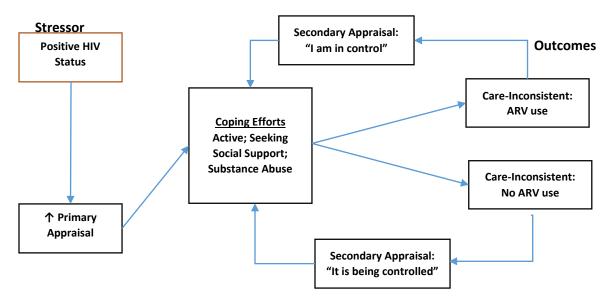


Figure 4.2: Model of Care Inconsistent MSM-LWH

## Care Detached MSM-LWH

With usage rates of over 50%, care detached MSM-LWH predominantly utilized emotion-focused coping strategies, including substance abuse and seeking out emotional support. In terms of problem-focused coping, these men also utilized restraint coping (Table 4.2). This preference for utilizing more emotion-focused strategies (i.e. substance

abuse and emotional support) suggests that care detached men addressed HIV related stress by focusing their efforts on adjusting their emotions rather than taking action steps.

Primary Appraisal. Utilization of more emotion-focused coping strategies was due to a lower perception of harm from HIV, which was a prevalent sentiment among care detached men. Reinforcement of this perception came in the form of providers advising against medication onboarding due to their positive clinical outcomes.

Medication onboarding refers to the initiation process in starting an ARV regimen. One participant said:

The first doctor was like, you don't need to, and I was just like, ok, sounds good to me. I didn't question it. I didn't ask anything else. He told me I didn't have to take medicine and that means I don't have to think about this, and put it out of my mind. – African American, age 33

A lower perception of threat was also facilitated by beliefs of "feeling healthy" and not experiencing severe HIV symptomology, similar to findings among the care inconsistent MSM-LWH.

There was no need for it because like I said my- my counts was pretty good. I haven't had no um, uh no major illness that required hospitalization or anything like that. — African American, 45

**Restraint.** The concept of "if it is not broken, don't fix it" was a prevalent theme among care detached men. When they exhibited a lower perception of the threat to their health, it nurtured an environment that facilitated the practice of restraint. They were essentially holding back from receiving treatment until they became "really, really sick". These men gave examples of extreme changes in health status as reasons they would engage in care and start ARV treatment.

Um my viral load would have to be probably in an all of a sudden jump from undetectable to maybe one or two hundred thousand and um, my so called t-cell count drop to zero. And um, and I would have to be getting a lot of illnesses like pneumonias [and] back to back hospitalizations. You have to get into the being in the hospital by yourself quite a few times before I'd even think about taking meds. – African American, age 45

The fact that these men do not want to start treatment until they perceive themselves as "broken" implies that ARV use has a negative effect on their HIV illness perception.

Some men stated their aversion to taking medication was related to its association with being sick; they hoped to delay that process for as long as possible. Until there is a cognitive admission and acceptance of "being sick", which could emerged due to poor lab values or the presence of physical HIV symptoms, these men will continue to utilize restraint coping, which becomes a barrier to receiving care.

I've decided to not take meds yet based on my CD4 and my viral load count numbers. I understand that once I start to take the HIV meds that you know I have to take them for the rest of my life. So I've decided to delay that process as long as I can. — African American, age 40

Substance Abuse. Another barrier involved the struggle with drug or alcohol addiction. While substance abuse was a deterrent from consistent ARV treatment among the care inconsistent, care detached men admitted that drugs or alcohol suppressed their memory of their HIV status, which became a barrier to care linkage. They also acknowledged the detrimental effects of using drugs as a stress reliever.

I really do think that's [drugs] a big interference because it be like when I'm not doing no drugs, alcohol or anything... I get to thinking that I really need-what I really need to do is to go and try to do it. But I still go back to my old ways and I know it's not good, but I'm trying to you know, get better...

- African American, age 43

Seeking Emotional Support. Unlike coping with substance abuse, many of the men in this group would cite emotional support as an effective stress reliever. As stated earlier, emotional support seeking would usually occur during status disclosure. However, many men in this group delayed the disclosure process. One participant admitted:

I never told a soul up until this year really. My first time telling anybody has been this year and it wasn't even like I planned to say anything about it, it was my newest boyfriend. — African American, 33

After delaying, some men explained that they decided to disclose and seek emotional support because they "couldn't hold it in" any longer. After disclosure, they noted feeling immediate relief, regardless of the reaction they received.

I told my best friend and another good friend about it. I was so overwhelmed, like depressed and stressed. It felt like my heart was ready to explode so I felt like I had to let someone know. I didn't want to let my family know because they are so like judgmental and I was scared to let them know. They still don't know to this day, so I told my best friend and another good friend. They were very easy on me. – African American, 25

**Secondary Appraisal.** Reinforcement of these coping strategies would be due to the prevalent sentiment of the disease being controlled and low self-efficacy. Low self-efficacy was a result of stable HIV clinical outcomes and being asymptomatic. Similar to the other care groups, care detached men believed that either their body was self-regulating the infection.

My body was feeling good period. My mind was at ease because I know everything, everything was controlled, and I think I was far for any complication, even though, you know, you can pneumonia or you can get cold or something, get wet outside might make things worse for yourself, but then at that point, I was like feeling well that, feeling good that I looked good, and I was doing what I was supposed to do. — African American, age 42

There were some who even cited a higher power ("God") as responsible for their good health.

Um, by the grace of God I haven't had any illnesses yet, as of yet. Um, that's as much as I can say about it...Well my viral load is still undetectable thank God. And my so called t-cell count is uh still um, still good and um, that's one of the reasons why I'm probably not taking anything. — African American, 45

Both justifications reinforced the continued used of restraint, substance abuse, and behavioral disengagement. Figure 4.3 depicts the typical process of coping among care detached MSM-LWH as it relates to the transactional model of stress and coping.

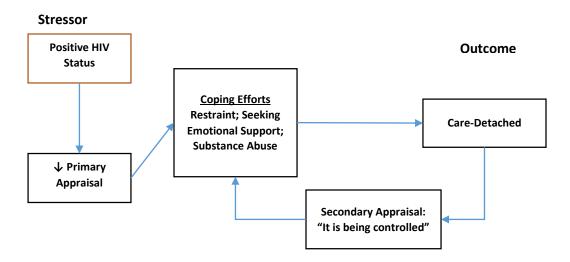


Figure 4.3: Model of Care Detached MSM-LWH

From the results above, active coping, planning and restraint coping strategies presented statistically significant utilization rates and was thematically saturated across

care continuum groups. However, denial ( $\chi 2=6.788$ ; p=0.028), and self-blame ( $\chi 2=5.222$ ; p<0.036) also revealed significant differences between the three care groups. Due to temporal and lack of saturation within the transcripts, denial and self-blame have been excluded from the thematic analysis. Lastly, additional narratives from the participants in each care group can also be found in Appendix C for further insight.

## **Chapter 5: Discussion**

This chapter will describe key findings based on the two proposed research questions, limitations of the present study, and implications and future directions of the field.

# **Key Findings on Research Question #1 and #2**

Among MSM-LWH, advancement toward viral suppression in the care continuum can be supported by the utilization of problem-focused compared to emotion-focused coping strategies. In this present study, active coping, planning, and seeking instrumental support were frequently cited as facilitators, fostering better HIV health outcomes through effectively decreasing stress and increasing engagement in HIV care. In terms of HIV as a chronic illness, there is evidence suggesting that problem-focused coping strategies are more effective in producing positive adaptation outcomes over the longterm compared to emotion-focused strategies (Fleishman & Fogel, 1994; Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998; Hudson, Lee, Miramontes, & Portillo, 2001). Specifically, Mulder et al. (1995) found a statistical trend suggesting that using active coping strategies predicted a decrease in HIV symptomology. Another study found that those seeking social support in the form of support groups reported less emotional distress (Kalichman, Sikkema et al. 1996). With the exception of seeking restraint coping, problem-focused strategies appear to build resiliency and thereby equip MSM-LWH with more effective ways to manage care and treatment.

In this study, the utilization of restraint and substance abuse were prominent barriers to movement through the care continuum. Literature has shown that these emotion-focused coping strategies were associated with poorer HIV health outcomes (Moskowitz, Hult, Bussolari, & Acree, 2009). Although there is sparse literature examining the impact of restraint coping, this strategy also emerged as a barrier to care in this study.

In terms of utilizing certain coping strategies as a response to HIV related stress, Chi square analyses revealed certain differences among the defined care continuum groups (e.g., active coping, planning, restraint, denial, and self-blame). Some of these results mirrored the differences found during qualitative analysis of the 84 interviews. Specifically, active coping and planning were primarily utilized by those who classified as care engaged, while restraint was utilized by care detached MSM-LWH. Table 5.1 displays the most common coping strategies used by each care continuum group. This table highlights the similarities and differences in coping strategy utilization among the care groups. MSM-LWH in the care engaged group primarily utilized problem-focused coping strategies, while care detached men mostly employed emotion-focused coping strategies (seeking emotional support and substance abuse), with the exception of restraint coping. Care inconsistent MSM-LWH used a combination of both coping strategies (emotion- and problem-focused coping).

**Table 5.1: Summary of Most Commonly Used Coping Strategies by HIV Continuum Care Group** 

Coping Strategy	Care Engaged	Care	Care Detached
		Inconsistent	
Problem-Focused Coping			
Active Coping	X	X	
Planning	X		
Restraint Coping			X
Seeking Instrumental	X	X	
Support			
Emotion-Focused Coping			
Seeking Emotional	X	X	X
Support			
Substance Abuse		X	X

In terms of problem-focused coping, care engaged and care inconsistent MSM-LWH both utilized active coping, which explains the action steps they took toward seeking out and adhering to care. Care engaged and care inconsistent men consistently sought out instrumental support in the form of advice. Restraint was more readily utilized by care detached MSM-LWH, by admitting to delay seeking any form of HIV care. Care detached and care inconsistent men turned to substance abuse. Among those who were care inconsistent, drugs and alcohol interfered with medication adherence through memory loss. Care detached men used drugs and alcohol to suppress their emotions and mitigate their stress. All care groups sought emotional support to relieve stress and receive compassion from others.

Overall, by identifying which coping strategies are utilized by the MSM-LWH in different care continuum groups, this study advances previous research on how these strategies impact HIV care outcomes. These results also provide a better understanding of the coping process among MSM in different care groups in relation to the transactional model of coping and stress. In addition to coping differences (i.e. problem-focused used

by care-engaged vs. emotion-focused used by care-detached) being found across all three care continuum groups, there were distinct differences in the appraisal of HIV related stress. In terms of primary appraisal, MSM-LWH who have a higher perception of susceptibility, usually due to negative experiences with HIV-related illnesses and symptomology, utilize strategies that facilitate ARV adherence (Gao et. al, 2000). This was commonly seen in care engaged and care inconsistent MSM-LWH in this study. Gao et al. (2000) also found that a low perception of threat led to inaction, which can explain care detached men utilizing strategies that inhibit taking steps towards ARV adherence.

Other differences involved the process of secondary appraisal. Although an evaluation of disease severity and threat (i.e. primary appraisal) usually occurs after learning about their status (refer to Figure 1.2), it was apparent that perception of control and self-efficacy (i.e. secondary appraisal) was directly related to their care continuum group status (i.e. health outcome). This is a slight departure from the original theoretical model, which states that primary and secondary appraisal directly influences the utilization of certain coping strategies, without the influence of the health outcome. All of these differences among the care continuum groups found in this study have direct public health implications.

## **Public Health Implications**

Essentially, ART is recommended for all PLWH, regardless of CD4 cell count, to reduce the morbidity and mortality associated with HIV infection (Famil, 2006). It is also recommended for PLWH to prevent the transmission of HIV. Despite these recommendations, MSM-LWH in the care continuum groups experience different barriers that prevent starting and staying on an ARV regimen. Study findings identified

differences in utilization of coping strategies across all three groups, which suggests that interventions tailored to each group would be more effective in improving coping outcomes and facilitating movement across the continuum towards viral suppression. Furthermore, because race/ethnicity and city location did not emerge as confounding variables, the following suggested interventions can relate to diverse MSM-LWH in all five cities.

Interventions for Care Engaged MSM-LWH. Findings from this study suggest that health care providers should take measures to help care engaged MSM-LWH remain in care. Health care providers should engage MSM-LWH in the health care process by using good communication, exploring patient beliefs about HIV care, learning more about individual patients in order to understand what motivates them to adhere to HIV treatment regimens (Gaston & Alleyne-Green, 2013). While this intervention would involve a combination of motivational interviewing and care readiness assessments, provider need to continue to strengthen relationship with their patients. Care engaged MSM would often cite their providers as reliable sources of instrumental support. Past literature also indicates that ARV adherence is associated with better provider-patient relationships (Schneider et al., 2004). Training providers on being culturally competent with health care delivery can improve communication between the patient and provider, especially among diverse MSM-LWH (Saha et al., 2013).

Interventions for Care Detached MSM-LWH. In the literature on stress and coping, self-efficacy refers to a person's ability to effectively manage their stress (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006). In this study, coping self-efficacy emerged during the secondary appraisal of HIV related stressors. High coping

self-efficacy was related to those engaged in care and on an ARV regimen, which reinforced the utilization of problem-focused coping strategies. MSM-LWH who demonstrated low coping self-efficacy were usually not on an ARV regimen nor engaged in any HIV care. Low perceived control or self-efficacy also reinforced utilization of emotion-focused coping strategies and ineffective problem-focused strategies (e.g., restraint). To assist MSM-LWH in moving toward increasing their coping self-efficacy, providers and other clinicians need to more readily incorporate coping effectiveness training (CET) practices into their interactions with this population. CET involves appraisal training that enables one to differentiate between malleable and unchallengeable aspects of stressors, tailoring application of particular coping strategies to specific stressors, and training to increase effectiveness in help seeking (e.g., social support) (Folkman et al., 1991). Application of this cognitive behavioral intervention for managing stress has demonstrated effectiveness in reducing perceived stress and burnout amongst MSM-LWH (Chesney, Chambers, Taylor, Johnson, & Folkman, 2003). In addition to improving coping self-efficacy, cognitive behavioral stress management techniques are also known to increase the use of active coping and coping through acceptance and decrease dysfunctional attitudes and coping through behavioral disengagement (Carrico et al., 2006). This intervention facilitates the utilization of more problem-focused coping strategies, which ultimately leads to better HIV health outcomes.

Another intervention utilizes the involvement of integrated support groups. Past studies of PLWH have shown a positive correlation between social support, ART adherence (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000), and remaining engaged with medical provider appointments (Catz, McClure, Jones, & Brantley, 1999). A recent

systematic review of the impact of support groups for PLWH revealed that implementation of support group interventions has a high positive impact on lower morbidity and higher retention in HIV care (Bateganya, Amanyeiwe, Roxo, & Dong, 2015). Although MSM in all three care groups sought out emotional support in response to HIV related stress, few care detached MSM-LWH sought out instrumental support. Many of the care engaged and care inconsistent men discussed seeking advice from fellow MSM-LWH peers. The integration of MSM-LWH from different care groups in a support group can provide an environment where care detached men, who typically attend support groups for emotional support, can receive advice from their peers. Through the increased interaction with peers in different care groups and the exchange of ideas, there is an increased likelihood of adoption of effective problem-focused coping strategies and changes in HIV threat assessment.

Interventions for Care Inconsistent MSM-LWH. While the care inconsistent men would benefit from the cognitive-behavioral intervention, CET, they encounter many barriers that need to be addressed simultaneously. Care inconsistent MSM would also benefit from a medication management intervention program, since they demonstrated a lack of using planning strategies to facilitate ARV adherence. It includes developing self-efficacy through a series of exercises, counseling sessions, and feedback of adherence performance using electronic monitors on medication bottles (Smith, Rublein, Marcus, Brock, & Chesney, 2003). Additionally, integration of substance abuse services in a HIV specialty setting could help reduce the negative effects their addiction has on HIV care. Table 5.2 depicts a summary of possible tailored interventions available to MSM-LWH by each care continuum group.

Table 5.2: Summary of Potential Intervention by Care Continuum Group

Care Continuum	•	
Care Engaged  Care Inconsistent	<ul> <li>Most use effective problem-focused coping strategies</li> <li>Low self-efficacy with ARV adherent</li> <li>Use ineffective emotion-focused coping strategies</li> <li>Lack of using planning strategies</li> <li>Still experience addiction</li> </ul>	<ul> <li>Motivational         Interviewing</li> <li>Cultural         Competency training</li> <li>Coping effectiveness         training (CET)</li> <li>Coordination of         social services</li> <li>Medication         management         program</li> <li>Integration of         substances abuse         services</li> </ul>
Care Detached	<ul> <li>Low self-efficacy with engaging in care</li> <li>Use ineffective emotion-focused and problem-focused coping strategies</li> <li>Lack of seeking out instrumental support</li> </ul>	<ul> <li>Coping effectiveness training (CET)</li> <li>Integrated peer support groups</li> </ul>

# **Study Limitations**

Although this study is an exploratory examination of coping strategies employed by African American and Hispanic/Latino MSM-LWH through the discussion of their HIV care histories, there were several research limitations. The analyses of associations between coping strategies and care continuum group are not generalizable past the sample because of the purposive sampling utilized in recruiting the study group. However, the discovered bivariate variations in coping strategies between continuum groups may also be subject to confounding by other sociodemographic or structural

factors, though the analysis suggest that city and race/ethnicity are not likely major sources of confounding. Analysis controlling for potential confounders might be well-suited to a follow-up study using a larger and probability-based sample.

The data collection instrument (interview guide) was aimed at discovering barriers and facilitators to HIV care. Although subscales of a quantitative measurement and mediating constructs of the widely used transactional model of stress and coping were used as the deductive framework of the codebook and drove the analysis, an interview guide specifically developed for this study might have provided more insight on the processes of coping with HIV related stress.

Additionally, due to the study's qualitative nature, participant self-reporting might have introduced recall bias, as information could not be independently verified and could have led to omission of relevant data, such as forgetting to mention a specific coping strategy utilized in the past. Another significant limitation to this study was the distribution of participants within the different HIV care groups. Although the sample size of this study was quite large, there were more participants categorized in the care engaged group, making it difficult to compare coping strategies within and across all three care groups.

### Conclusion

In this study, there were distinct differences in the utilization of coping strategies among MSM-LWH in different care groups. Problem-focused coping strategies were predominantly utilized by those who demonstrated effective HIV care behaviors, while emotion-focused coping strategies were consistently used by MSM-LWH who exhibited

negative HIV care behaviors. This suggests that certain problem coping strategies serve as facilitators and barriers to movement across the HIV care continuum. Future interventions need to consider tailoring their activites according to the needs and characteristics of MSM-LWH in the different care continuum groups (i.e. care-engaged; care-inconsistent; care-detached) to increase adoption of effective coping strategies and facilitate movement across the care continuum.

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# Appendices

## Appendix A

Codes	Definitions	Examples
Primary Appraisal	Evaluation of the significance of a stressor or threatening event.  Perceptions of an event as threatening can cause distress.  If an event is perceived as positive, benign, or irrelevant, little negative threat is felt.	"Well I understood that my t-cells were high enough and my viral load was where it's supposed to be that they could not even recommend – why fix something that's not broke."
Secondary Appraisal	Evaluation of the controllability of the stressor and a person's coping resources  Perception of one's ability to change the situation, manage one's emotional reaction, and/or cope effectively can lead to successful coping and adaptation.	"That I have control. It does not control me so- today I'm a better person from, I'm a better person. I can't compare myself to any other people because I don't know anyone else. I do know other people but I don't know anyone else who has achieved as much as I have because I do believe in more education, to better yourself- the more you help yourself by wiping that stigma away and I think that's really what it is- that stigma."
Coping Efforts	Actual strategies used to mediate primary and secondary appraisals	See in the coping strategy codebook

## Appendix B

Codes	COPE Inventory (CI)/Brief COPE (BC) Items	Definitions	Examples
Active Coping	<ul> <li>I've been concentrating my efforts on doing something about the situation I'm in. (BC)</li> <li>I've been taking action to try to make the situation better. (BC)</li> </ul>	Active coping includes initiating direct action, increasing one's efforts, and trying to execute a coping attempt in stepwise fashion. Descriptions of taking action steps to deal with his HIV diagnosis and treatment. Also includes descriptions of actions that can ameliorate the stress of living with HIV (doesn't include substance abuse, alcohol and avoidance coping).	" I see the doctor regularly cause he knows about it so once I go get my regular checkup we discuss my HIV as wellSo I combined it all at once so that's every three months or every two months or if I need to get blood tested I'll come back the second week of my you know just to get the results."
Planning	<ul> <li>I've been trying to come up with a strategy about what to do. (BC)</li> <li>I've been thinking hard about what steps to take. (BC)</li> </ul>	Descriptions or statements of thinking about dealing with the problem. It also includes discussion of and coming up with action strategies to best handle their situation. It also includes statements of plans to start taking action steps to seek care.	"Yeah pill boxes for me and I have four pill boxes so I have, so when I set my medication up, it's set up for the month because you one pill is- take you through a week So your four will take you through the month. So I set it up for the month and go from there and that really helps me. I couldn't you know, take a pill out the bottle and – cause I couldn't remember if I take it or not."

Use of instrumental support	<ul> <li>I've been getting help and advice from other people. (BC)</li> <li>I've been trying to get advice or help from other people about what to do. (BC)</li> </ul>	Description of seeking out or receiving advice from other people. It was includes receiving assistance in the form of information, food, housing, transportation, money, or any other tangible support.	"Um yes, yes. When I contracted diabetes, when I found out I had diabetes I think I flipped out a little bit because I got scared cause the doctor was talking about oh you could have stroke or you could die or you could do this and my mind said ok you need to go talk to somebody cause you're going to flip. So I went to a psychiatrist about it, you know, and we talked and I talked extensively about stuff and then you know and um, and I had gotten to the point that I had gotten depressed about it so therefore- and I don't, I did take some medication for that."
Acceptance	<ul> <li>I've been accepting the reality of the fact that it has happened. (BC)</li> <li>I've been learning to live with it. (BC)</li> </ul>	Statements of accepting their HIV diagnosis or descriptions of learning to accept their status.	"so we played the blame game and for a long time we didn't really talk about it we just played the blame game and went on our daily lives until we came down uh sat down and said we really need to discuss this because we have a son and we're, we're going to die if we don't do something about this you know. So we need to get into treatment, we need to do what we need to do to survive this."

Positive reframing	<ul> <li>I've been trying to see it in a different light, to make it seem more positive. (BC)</li> <li>I've been looking for something good in what is happening. (BC)</li> </ul>	Mentions of having an optimistic outlook about their HIV diagnosis; descriptions or trying to be more positive; trying to highlight the benefits of their situation.	"So it's like- it makes me want to live the way I'm living now like how I started living again. It's like ok, there's nothing to hide really, cause you got people with HIV who don't even die from HIV, they die from something totally different, you know so I shouldn't let that stop my life now."
Use of emotional support	<ul> <li>I've been getting emotional support from others. (BC)</li> <li>I've been getting comfort and understanding from someone. (BC)</li> </ul>	Descriptions of having a confidant or multiple people that provide comfort; also describes having a person that can listen or provide sympathy.	"My brother and sister give me 100 percent support, particularly my sister. We have a great relationship. She is always asking how I'm doing, tries not to, you know, do—for me not to get too upset or nervous about anything because of my health. She worries about my stress. It's a very negative load if you are HIV positive and she knows that."
Denial	<ul> <li>I've been saying to myself "this isn't real".</li> <li>(BC)</li> <li>I've been refusing to believe that it has happened. (BC)</li> </ul>	Discussion of being in denial; refusal to believe their HIV diagnosis (This can include references to the past).	"It was lot to take in, you know, so it was only, you know um, it was as- you know it would only be expected that it would take some time you know, just like it took me some time. I didn't accept it overnight and I, you know, it would be

			unrealistic for me to expect for them to."
Self-blame	<ul> <li>I've been criticizing myself. (BC)</li> <li>I've been blaming myself for things that happened. (BC)</li> </ul>	Statements of self-blame or criticism about their HIV status.	"Well, you know, you had unprotected sex, you did this, that and the other, that's what you get."
Self-distraction	<ul> <li>I've been turning to work or other activities to take my mind off things. (BC)</li> <li>I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. (BC)</li> </ul>	Mentions of distracting oneself from thinking about their status. Includes mentions of avoidance, but doesn't include distractors like substance abuse.	"I kind of refrained from sex a lot, but as much as I could and just lived a normal life. Partying and going out doing what I normally do and you know until I got older- out of my twenties and I realized that this is serious and I had to start taking care of myself more and when I realized that I actually started looking for myself"
Substance Use	<ul> <li>I've been using alcohol or other drugs to make myself feel better.         (BC)         I've been using alcohol or other drugs to help     </li> </ul>	Descriptions of using alcohol or other drugs to alleviate stress; help get through dealing with their status; mentions of any substance use.	"Yes, right after diagnosis. I got involved in heavy drug use, alcoholic, drinking more and more, trying to subdue the thinking process and drown the emotions that I was dealing with."

	me get through it. (BC)		
Restraint	<ul> <li>I restrain myself from doing anything too quickly. (CI)</li> <li>I hold off doing anything about it until the situation permits. (CI)</li> <li>I make sure not to make matters worse by acting too soon. (CI)</li> <li>I force myself to wait for the right time to do something. (CI)</li> </ul>	Statements of waiting for the right moment to act or delaying until necessary. This also includes waiting to start treatment until an appropriate opportunity to act presents itself and holding oneself back.	"I mean I would have to get sick. Sick, sick, really sick [to start medication]."
Religion	<ul> <li>I've been trying to find comfort in my religion or spiritual beliefs.         (BC)</li> <li>I've been praying or meditating. (BC)</li> </ul>	Description of using faith for support; also includes mention of their religion, "God", spirituality, the bible and other religious references.	"So that's one of the reasons (coughs) excuse me, that's one of the reasons when you was asking- when you was asking well what made you, you know, decide to be tested this time- I just think that you know, the reason I said that it was time because I think God had prepared me, or my higher power had prepared me for and um, you know, if when all the support and everything was

			there and he knew that I could handle it."
Behavioral disengagement	<ul> <li>I've been giving up trying to deal with it. (BC)</li> <li>I've been giving up the attempt to cope. (BC)</li> </ul>	Mentions of giving up trying to deal with their diagnosis (This can include references to the past).	"I was scared because I just didn't- I didn't feel like thinking about having HIV you know. I didn't feel like thinking about it".
Venting	<ul> <li>I've been saying things to let my unpleasant feelings escape. (BC)</li> <li>I've been expressing my negative feelings. (BC)</li> </ul>	Descriptions or statements of the men living with HIV having the tendency to focus on whatever distress or upset one is experiencing and to ventilate those feelings	"I was stressed out. I felt like my heart were ready to explode I was just holding so much in and it was hurting me. I just felt like I needed to tell someone. I were at work and I was crying and stuff. I've been at my job for 6 years and no one have ever seen me at work cry or anything. I had a friend, she was concerned. She's been working there for about a year, but she was concerned, and she was asking me what was wrong, and I didn't tell her or anything. I was just saying that I was going through some things, like I'm really going through some things. She was like, maybe you need to talk to someone. I was telling her that I was too scared to tell anyone my business, and she was like, maybe you need to talk to someone.

		You have a best friend. Let your best friend know."

### **Appendix C**

### Additional Quotes Related to Coping across three HIV Care Continuum Groups

### **Care Continuum Group Quotes**

#### Care Engaged MSM-LWH

Primary Appraisal

I went to jail one time and caught staph. I went to jail again a few months later and caught staph again and that scared me and I felt like ok my immune system must be dropping behind my drug usage. So the doctor talked to me about he said we know that one cocktail and she convinced me to will you just try... I said ok I'll take it. So since I've been taking [medication name] since 2008. I haven't had any side effects.

– African American, 49

**Active Coping** 

Well, I feel that it's like a whole balance. I have to make sure that I have a balance of, you know, making sure that I am taking my medication every day. I take vitamins on a daily basis, and I, you know, I exercise regularly, and then I don't eat too much, too many bad foods.

- Hispanic, 37

**Planning** 

On my cell phone, I put in my doctor visits. I also put it on my calendar. I put it on my calendar on my cell phone. It's gotten habitual with me. When I get up in the morning, I know I'm going to take my medicine. I can get downstairs and I'll go "medicine"! Then I'll go back upstairs and it's like engraved into my head now.

- African American, 55

Secondary Appraisal

My body was feeling good period. My mind was at ease because I know everything, everything was controlled, and I think I was far for any complication, even though, you know, you can pneumonia or you can get cold or something, get wet outside might make things worse for yourself, but then at that point, I was like feeling well that, feeling good that I looked good, and I was doing what I was supposed to do.

– African American, 51

#### **Care Inconsistent MSM-LWH**

Primary Appraisal

I know in this—I'm sorry to interrupt you—but in this topic, like I know I'm an ignorant person cause, no, I know I am cause once they tell me that I'm healthy, that I'm undetectable, then I always get it in my mind, well, if I'm healthy and undetectable, then that's even better, so I don't have to take so and so days of medicine.

– Hispanic, 27

**Active Coping** 

I just plan on taking my meds as I should. And live. That's my treatment and care. I do go to the doctor, I don't go as I should but I make sure that I do things that keep me healthy that I know is common sense. I try to eat right, try to exercise, try to have protected sex because I do know that there's other things I could still get that could eventually hurt me. So, that's my plan just to take my medicine and, and live. — African American, 26

Substance Abuse

Yeah, without stopping, and that's when I don't keep track of my medications and I lose them. And right now that happens and I can't find a job, and all that I get deeper into the alcohol.

- Hispanic, 33

Secondary Appraisal

Well, when the doctor reads to me the viral load and all that, I just listen to him and I say, Oh my god. I worry, but at the same time, I don't know what to do about it.

- Hispanic, 35

Well lately, I honestly, it's been like one out of seven... Cause I've really gotten bad with it, but this is why it's weird for me cause when I come and get tested, whether it's a month that I've forgotten a little bit here and there or whether it's I took them every day, my results are always the same. I'm always undetectable.

Hispanic, 32

#### Care Detached

Primary Appraisal

I don't see that's needed cause — I feel like it's — I don't- see I've never been sick, I never — I have nothing has ever been wrong with me, you know, nothing. I haven't been waking up in the morning sick or diarrhea or whatever; the symptoms I never had so that's why — that's one of the reasons why I don't go down to the health department.

- African American, 47

Restraint

Yes, if I went to the doctor and they said that I need to, or if it's getting higher, then I'll say yes, I'll take it.

– African American, 22

Substance Abuse

So sometimes I'll start the pills and then I'll be under the influence and I'll stop it and cause I'm afraid, you know, that it might mess me up or, you know?

- Hispanic, 31

Secondary Appraisal

When I didn't go to drugs and the drinking, [I] was ok, but when I stopped doing the cocaine and marijuana then I can... I maintain my medicine and I did what I was supposed to do and made all my appointments on time. I went to counseling meetings and all that, but soon as I go back to doing cocaine you know it's like um defects in my mind or something, like the anger build up and I take my problems out on other people and I don't listen what they say, which I know is not good.

- African American, 43

#### **All Continuum Groups**

Seeking Instrumental Support

He helps me, reminds me, makes sure everything is on the table. He cooks, give me medication I don't gain no weight.

-African American, 45

Seeking Emotional Support

Because they're my friends, my closest friends and they are also infected. So, I identify more with them. They first told me about themselves and maybe that's why I opened up to them too, and I told them so am I and so there's a sort of brotherhood, you don't feel alone and they'll tell you about, Oh, I know about such and such place where you can go get this or that, you can get help. And that motivates you a bit more, you feel more, you feel safer

– Hispanic, 35