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Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality
of Life in People Living with HIV/AIDS

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An abstract of
A dissertation submitted to the Faculty of the
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Abstract

HIV-related stigma, Coping, Social Support and Health-related quality of Life among blacks living with HIV/AIDS

By Hanna Bewketu Demeke

Background: HIV/AIDS disproportionately affects African Americans. The proportion of foreign-born black people living with HIV/AIDS (PLWHA) is significant and will continue to increase with the repeal of travel ban in 2010. The perception of and coping with HIV-related stigma and its consequence may vary as well. There is lack of comparative study in this area.

Purpose: This study examines the relationships between perceived HIV-related stigma, coping strategies, perceived availability of social support and health-related quality of life (HRQoL) and compares native-born and foreign-born black PLWHA.

Methods: This is a cross-sectional comparative study guided by the Transactional model of Stress and Coping. Multidimensional measure of internalized HIV stigma scale, the Brief COPE scale, medical outcomes study social support survey, and the second version of short form health survey were used to assess key variables. Data were analyzed using descriptive statistics and bootstrap method to examine the mediation effects of avoidance coping and moderation effect of nativity and social support.

Findings: Thirty seven English-speaking foreign born and 63 native born blacks living with HIV participated. Compared with native participants, foreign-born participants were more likely to be female, heterosexual, a non-drinker and non-smoker, to live with someone, be diagnosed with AIDS and not to disclose their HIV status. Foreign-born patients had significantly higher HIV-related stigma and lower social support and had lower mental summary scores of HRQoL (MCS) than native patients. However, no significant differences were found in their use of coping strategies and physical summary scores of HRQoL. The relationship between HIV-related stigma and MCS was mediated by avoidance coping for native-born participants, but it was not for foreign-born groups. The relationship between HIV-related stigma and MCS was mediated by avoidance coping for those who perceived low social support group, but it was not for those who perceived high social support.

Discussion: These findings highlight the significant differences between native and foreign-born HIV-infected blacks. Interventions targeting coping strategy and social support need to consider differences and similarities between native and foreign-born groups. This study contributes toward developing a sound understanding of the growing population of foreign-born blacks living with HIV/AIDS.

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I dedicate this dissertation
in memory of my father,

Bewketu Demeke Alemu

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Lists of abbreviations

| | |
|---------|--|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Antiretroviral Therapy |
| CD4 | Cluster Designation 4 (T helper cells are responsible for coordinating much of the immune response. HIV's preferred targets are cells that have a docking molecule called "cluster designation 4" on their cells). |
| CDC | Centers for Disease Control and Prevention |
| DCBOH | DeKalb County Board of Health |
| HIV | Human Immunodeficiency Virus |
| MOS-SSS | Medical Outcomes Study-Social Support Survey |
| MCS | Mental Component Summary |
| PCS | Physical Component Summary |
| PLWHA | Persons Living with HIV/AIDS |
| RWECC | Ryan White Early Care Clinic |
| SF12v2 | Second version of Short Form Health Survey |
| TSC | Transactional Model of Stress and Coping |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| US | United States |
| WHO | World Health Organization |
| QoL | Quality of Life |
| HRQoL | Health-related Quality of Life |

CHAPTER ONE: INTRODCUTION

Introduction

Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) is a worldwide pandemic that has been in existence for three decades. Racial and ethnic minorities in the United States have remained disproportionately affected despite relentless efforts to prevent and control HIV transmission. It is estimated that every year nearly half of newly infected individuals are black or African American (CDC, 2011). Although the national HIV/AIDS surveillance and monitoring forms include country of birth, collection and reporting of these data have mainly focused on broad categories of race/ethnicity such as African American and Hispanic. Since foreign-born black individuals are categorized in African American race in several states, experts suggested that the increasing number of foreign-born black people living with HIV/AIDS (PLWHA) might have been confounding the statistics on African Americans. Grouping foreign-born and native blacks together misses important variations on demographic characteristics, risk, and health care seeking behaviors within this population (Ashton et al., 2012; Johnson, Hu & Dean, 2010; Kerani et al., 2008; Read, Emerson & Tarlov, 2005).

Ongoing changes in the health care system and policies are expected to improve access to care for all PLWHA. For example, the travel ban, which restricted HIV-positive non-citizen residents from changing their status to a legal permanent resident, had caused foreign-born individuals to go underground so that their HIV status remained unknown (Levy et al., 2007; Othieno, 2007). Thus, the rescinding of the travel ban (CDC, 2009) is expected to draw more foreign-born individuals, who knew or may not know their HIV status, to the health care system

of the U.S. without being afraid of the consequences to their immigration status. With a growing number of foreign-born black PLWHA living in the U.S., HIV-related stigma ingrained within the diverse culture of black immigrants will be the biggest challenge of HIV care and management for this population.

Conceptualization of stigma evolved to include not only a cognitive phenomenon at the individual level but also a complex social process at the community level (Mahajan, Sayle & Patel, 2008). HIV-related stigma is conceptualized in this study as a social construction of an attribute influenced by both individual predisposition and structural factors which affect the experience of PLWHA. Researchers reported that HIV-related stigma is associated with delayed presentation to health care, isolation, disclosure of HIV status to fewer people, discontinuation of care as a means to avoid mistreatment resulting from HIV-related stigma among Latino and Asian/Pacific Islander PLWHA living in the U.S. (Enriquez et al., 2010; Kang, Rapkin, & DeAlmeida, 2006; Levy et al., 2007). However, there is limited research about how stigma affects foreign-born black PLWHA.

Two qualitative studies, conducted among African-born PLWHA living in the U.S. revealed the presence of overwhelming impact of HIV-related stigma among this group (Koku, 2010; Othieno, 2007). Recent studies in other developed countries such as the U.K, Europe and Canada identified HIV-related stigma as a major hindrance to prevention and care of foreign-born black PLWHA (Anderson et. al. 2008; Lawson et al., 2006; Logie, James, Tharao & Loufty, 2013; Loufty et al., 2012; Ndirangu & Evans, 2009; Noh et al., 2012; Prost, 2005; Stutterheim et al, 2012a; Stutterheim et al, 2012b). Differences in immigration policies and health care systems between those countries make challenges of foreign-born blacks and their way of adaptation different. Therefore, those research findings do not fully represent the challenge and experience

of foreign-born blacks in the U.S. In order to better serve the growing population of foreign-born black PLWHA in the U.S., similarities and differences between foreign-born and native-born black groups should be identified and addressed.

This cross-sectional study was designed to examine the relationships among perceived HIV-related stigma, coping strategies, perceived availability of social support and health-related quality of life among foreign-born black PLWHA compared with native-born black PLWHA. Perceived HIV-related stigma affects many of the choices PLWHA make about seeking assistance for their physical, psychological and social needs. The fear of HIV-related stigma and the degree to which it is experienced by PLWHA have been reported to be substantially greater among black PLWH living in Europe (Dodds, 2006), U.K. (Elford, Ibrahim, Bukutu & Anderson, 2008), Canada (Lawson et al., 2006; Loufty et al., 2012; Prost, 2005) than among white PLWH. This comparative study contributes to the knowledge of what is similar and different between foreign-born and native-born black groups in the context of HIV-related stigma and related factors in the U.S. It also helps identify appropriate strategies to improve health policies and procedures that bring the unique cultural, social, and background variations into consideration.

Statement of the problem

According to a CDC report (2011), African Americans or blacks were the racial/ethnic group most affected by HIV in the United States. African Americans made up only fourteen percent of the U.S. population in 2009, but accounted for 44 percent of all new HIV infections occurring in the same year (CDC, 2011). In 2007, HIV was the ninth leading cause of death for all blacks and the third leading cause of death for all black women and black men aged 35 to 44. HIV-related stigma, fear, discrimination, homophobia, and negative perceptions about HIV

testing are among the top reasons believed to place too many blacks at higher risk of HIV infection since those factors are linked to HIV prevention and treatment (CDC, 2011). National surveillance and monitoring of HIV/AIDS have mainly focused on broad categories of race/ethnicity such as African American and Hispanic. Since foreign-born blacks are often categorized as African American race, their unique characteristics and issues were not addressed (Ashton et al., 2012; Johnson, Hu & Dean, 2010; Kerani et al., 2008; Read, Emerson & Tarlov, 2005).

Although the overall number of foreign-born black PLWHA that contributes to the prevalence of HIV African Americans in the United States is not clear, researchers are indicating a growing number of proportions of foreign-born black PLWHA. Karani and colleagues (2008) found that up to 50% of newly reported HIV diagnoses in blacks during 2003-2004 occurred among African-born persons in selected states of the United States with large African-born immigrant populations, including the State of Georgia. At a larger scale, Johnson, Hu and Dean (2010) reported that 11.2 percent of black adults and adolescents diagnosed with HIV infection between 2001 and 2007 were foreign-born in 33 states, for which country-of-birth information was available. Most of them were from the Caribbean (54.1 percent) and Africa (41.5 percent). This data affirm the significant number of foreign-born black PLWHA residing in the U.S. Furthermore, recent publications on the epidemiology of foreign-born black PLWHA in the U.S. indicated the clear difference in the characteristics of native-born and foreign-born black PLWHA such as gender composition, sexual practice, and health seeking behaviors. Foreign-born black PLWHA were more likely to be female, heterosexual, categorized under no reported risk of transmission, and had late entry to HIV care (Ashton et al., 2012; Johnson, Hu & Dean).

As the characteristics of native-born and foreign-born black PLWHA differ, so does the ways they perceive and handle HIV-related stigma. The perception and experience of HIV-related stigma among foreign-born black PLWHA may vary in its source, pattern and complexity from the U.S. native-born black PLWHA (Koku, 2010). Foreign-born black PLWHA experiences of and responses to stigmatization are shaped largely by cultural and religious assumptions, and perceptions about HIV learned from their countries of origin, and the western media's construction of HIV (Koku, 2010). A study among minority respondents reported that those who claimed their country of origin was not the U.S. were more likely to indicate two or more stigmatizing attitudes toward PLWHA than those who claimed the U.S as their country of origin (Darrow, Montanea, & Gladwin, 2009). Since foreign-born individuals tend to live in clusters, the level of stigmatizing attitude exhibited toward PLWHA in their community has significant impact on foreign-born PLWHA. Furthermore, foreign-born PLWHA suffer layering stigma as they possess other devaluing identities related to their immigration (Dodds, 2006; Nyblade, 2006).

Despite the increasing number of foreign-born black PLWHA in the U.S. and the known impact of HIV-related stigma, little has been done to explore the experience of foreign-born black PLWHA living in the U.S as it relates to HIV-related stigma, particularly in comparison with the native-born black PLWHA experience. Most of the HIV/AIDS studies in the first place focused on the general foreign-born population rather than the foreign-born PLWHAs (Beyene, 2000; Brooks, Etzel, Hinojos, Henry, & Perez, 2005; Hoffman et al., 2008; Rosenthal et al., 2003; Shedlin et al., 2006; Sheldin & Deren, 2002). Furthermore, the few studies found conducted among foreign-born PLWHA are predominantly among Latino PLWHAs (Bianchi, Zea, Poppen, Reisen, & Echeverry, 2004; Enriquez et al., 2010; Levy, 2007; Rameirez-Valles,

Fergus, Reisen, Poppen, & Zea, 2005; Rio-Ellis et al., 2008) and Asian/Pacific Islanders (Chng, Wong, Park, Edberg, & Lai, 2003; Kang et al., 2006; Yoshioka & Schustack, 2001). To the knowledge of the principal investigator, there is no quantitative research comparing the prevalence and impact of HIV-related stigma between foreign-born and native-born black PLWHA experience in the U.S.

This study examined the relationships between the level of perceived HIV-related stigma, coping strategies, level of perceived availability of social support and the health-related quality of life (HRQoL) and compared native-born and foreign-born black PLWHA in the context of this relationship. This study was guided by the transactional model of stress and coping. The unique personal, social, and environmental context of foreign-born black individuals such as the stress of resettlement in to a new culture and ingrained socio-cultural norms that strongly associate HIV transmission with activities perceived to be immoral set foreign-born blacks apart from native population. As a result, the primary investigator hypothesized that foreign-born black PLWHA would have higher level of perceived HIV-related stigma, difficulty coping with HIV-related stigma, and a lower level of social support and poorer HRQoL compared to U.S. born black PLWHA participants. Specific research questions and related hypothesis (H) were:

Question 1: Are there differences between native-born and foreign-born black PLWHA on HIV-related stigma, coping strategies, social support and HRQoL?

Hypothesis 1-A: Foreign-born black PLWHA have a higher level of perceived HIV related stigma than native-born black PLWHA.

Hypothesis 1-B: Foreign-born black PLWHA use more avoidant coping strategies than native-born black PLWHA.

Hypothesis 1-C: Foreign-born black PLWHA have a lower level of perceived social support than native-born black PLWHA.

Hypothesis 1-D: Foreign-born black PLWHA have a lower level of HRQoL subscales (Physical and Mental) than native-born black PLWHA.

Question 2: Does avoidance coping strategy mediate the relationship between perceived level of HIV-related stigma and mental summary score of HRQoL?

Hypothesis 2-A: The level of perceived HIV-related stigma would have a significant inverse effect on a mental summary score of HRQoL.

Hypothesis 2-B: There will be an indirect effect between the level of HIV-related stigma and mental summary scores of HRQoL through avoidance coping. The change in the level of perceived HIV-related stigma would be significantly and positively related to the use of avoidance coping strategies, which, in turn would be significantly and negatively related to the mental summary score of HRQoL.

Question 3: Does nativity moderate the mediation effect of coping strategy between perceived HIV-related stigma and mental summary score of HRQoL?

Hypothesis 3-A: Nativity moderates the relationship between perceived HIV-related stigma and mental summary score of HRQoL. This relationship will be weaker or absent for native-born black PLWHA than foreign-born black PLWHA.

Hypothesis 3-B: Nativity moderates the indirect effect of avoidance coping between perceived HIV-related stigma and mental summary score of HRQoL. The indirect effect will be different between native-born and foreign-born black PLWHA. The indirect effect will be weaker or absent for native-born black PLWHA than foreign-born black PLWHA.

Question 4: Does perceived social support moderate the mediation effect of coping strategy between perceived HIV-related stigma and mental summary score of HRQoL?

Hypothesis 4-A: Perceived social support moderates the relationship between perceived HIV-related stigma and mental Summary score of HRQoL. This relationship will be weaker or absent for high than low perceived social support categories.

Hypothesis 4-B: Perceived social support moderates the indirect effect of avoidance coping between perceived HIV-related stigma and mental summary score of HRQoL. The indirect effect will be different between low and high perceived social support categories. The indirect effect will be weaker or absent for high than low perceived social support categories.

Theoretical Framework

Transactional Model of Stress and Coping

The transaction model of stress and coping (Lazarus and Folkman, 1984; Wenzel, Glanz, & Lerman, 2002) provided the theoretical framework for this study. Conceptualization of stress and health has historically taken two approaches: theories based in physiology (Selye, 1956) and theories based on psychology (Lazarus & Folkman, 1984). The second approach, known as the Lazarus and Folkman stress theory, focuses on the impact of stress and the mitigation of its harmful effect. Lazarus and Folkman (1984) view psychological stress as a transactional phenomenon that is dependent on the meaning of the stimulus or environmental change to the perceiver. The fundamental concept is that individuals perceive stressful events in different ways and their cognitive appraisal of an event as potentially endangering to one's well-being subsequently influences one's coping strategy (Lazarus & Folkman, 1984). The study of psychosocial stress and health has also evolved from understanding the concept of stress and the

mediating pathways through which stress takes a toll on different aspects of health to the maintenance of well-being and resilience in the face of stress (Folkman, 2011).

Wenzel, Glanz, and Lerman's (2002) summary of the Transactional Model of Stress and Coping (TSC) includes recent developments of this theory and its application to health outcomes. In TSC, the meanings and perceptions of the stressful events (cognitive appraisals) are the main determinants of the coping strategy used. The effect on subsequent health behaviors and outcomes depends on available social support. This study explores how PLWHA dealt with perceived HIV-related stigma. TSC was selected to guide this study because of the emphasis on individual and group differences in the vulnerability to stress, and interpretation and response to stress. Concepts of TSC and applications are discussed below.

Concepts

Stress is defined as a relationship between a person and his/her environment that is perceived as taxing by the person and endangering to the person's well-being (Lazarus & Folkman, 1984). Any impediment encountered in life introduces some degree of stress depending on how the person perceives it as a threat. Perception of stressful events as a threat, however, depends on antecedent characteristics of a person and his/her environment. Those characteristics may increase either the resistance or the vulnerability of a person to stress. For example, positive previous experience and problem solving skills may increase resistance to stress while lack of information, resources and a negative previous experience may increase vulnerability to stress. According to Lazarus and Folkman (1984) these antecedent characteristics provide a context for understanding differences in how individuals appraise and cope with stressful events.

Cognitive appraisal is the process of perceiving, assessing, and evaluating of a given

situation. The person facing a problem evaluates the gravity and threat of the situation and determines how dangerous or controllable it is. According to Lazarus and Folkman (1984), there are primary and secondary appraisals. Evaluation of the susceptibility to and severity of the threat are considered the primary appraisal. The individual's assessment of the options and available resources to determine his/her ability to manage the stressful situation is considered the secondary appraisal. Through the combination of primary and secondary appraisals, the person determines the coping strategies to be used (Wenzel et al., 2002).

Coping is an individual's attempt to manage a stressful circumstance and minimize its negative impact. Coping is defined as "constantly changing cognitive and behavioral efforts to manage stressful demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Coping mediates the demand of the stressor on the outcome of the stress experience. Lazarus and Folkman (1984) conceptualized coping along two dimensions: problem-focused and emotion-focused coping. Problem-focused coping strategies (e.g., active coping and problem solving) are directed at changing the stressful situation, whereas emotion-focused coping strategies (e.g., avoidance and denial) are directed at changing the way one thinks or feels about a stressful situation. Problem-focused coping is an adaptation for stressors that are changeable while emotion-focused coping is when a person perceives the stressful situation to be unchangeable or when all problem-focused coping attempts have been made. The two dimensions are two distinct constructs, not two opposite poles in a single continuum (Folkman & Lazarus, 1980; Schmitz & Crystal, 2000). The actual coping strategy used to control a problem gives rise to the outcomes of the coping process.

Social support is defined in terms of social network and availability of social provisions. Social provision consists of the functional aspect which is the positive interaction and supportive

actions within the social network. Folkman, Chesney, Pollack, and Phillips (1992) suggested that the social aspect of coping such as the use of spirituality and seeking of social support may be the key factor to understanding the difference between those who engage in undesirable outcomes and those who do not. Wenzel and her colleagues outlined three possible paths in which social support influence the stress coping process. First, one's social network and availability of social provisions can serve as a coping resource that directly affects secondary appraisal. Second, one's social network and availability of social provisions provides opportunities to explore different coping options which influence the coping strategies used. Finally, the individual's perception of their social network and available social provisions can change the adaptation outcome by affecting the actual coping strategies. Thus, the actual social network and available social provisions can be considered as coping resources while individual differences in perceived social support can be considered as a moderator of the impact of stress on the coping process and outcome (Wenzel et al., 2002). That is, the secondary appraisal of a specific stressful event and its effect on the coping strategies as well as the adjustment of a person may depend, in part, on his or her perceived and received support in the environment that produces a modifying interaction.

The outcome is the person's adaptation to stress. An individual's cognitive appraisal of the stressful event, as well as their available resources, influences the actual coping effort leading to an adaptation to the stress. According to Lazarus and Folkman (1984), adaptation to stress can be categorized into three major outcomes: emotional, functional and subjective well-being. Emotional well-being includes psychological states and related somatic symptoms. Functional well-being includes the way in which individuals satisfy various roles. Subjective well-being relates to how individuals feel about their life including life satisfaction and quality of life.

Wenzel and her colleagues described health status outcome in TSC, which include functional and subjective well-being as an adaptation to stress (Wenzel et al., 2002).

Applications of Concepts to the Study

As depicted in Figure 1, HIV infection and nativity are antecedent factors that provide the context to understand how, if at all, native and foreign-born black PLWHA differ in dealing with stigma. The stress of HIV-related stigma is the focus of this study. PLWHA perception of the HIV-related stigma is their cognitive appraisal of HIV-related stigma as a threat. PLWHA will determine the coping strategies they use depending on how they perceive the threat of HIV-related stigma and the availability of social support. The coping strategy mediates the effect of HIV-related stigma and its outcome. The coping strategies give rise to outcomes of the coping process, which is health related quality of life (HRQoL). Finally, HRQoL is an individual's perception of well-being in the physical, mental, and social domains of life that can be clearly shown to affect health (CDC, 2000).

Nativity as Antecedent Characteristics

PLWHA confront HIV-related stressors including fear of stigma and discrimination, coping with the uncertainty of the course of the illness, and changes in HRQoL (Ironson & Kremer, 2011; Remien & Mellins, 2007). The intensity of the stressors, however, varies with social and economic status of the person or group. For instance, PLWHA who were members of racial or ethnic minority, had low levels of income or education, were not a native English speaker, or were heterosexual reported higher level of stigma (Sayles et al., 2008). Foreign-born black PLWHA face intense HIV-related stigma and deal with it in different ways than native-born black PLWHA (Koku, 2010; Shedlin et al., 2006). Immigration and acculturation processes also increase a foreign-born individual's vulnerability to stigma (Dodds, 2006). Social

inequalities, poverty, and difficulties in accessing health services are common phenomena that are associated with higher perceived levels of stigma among foreign-born (Castro & Farmer, 2005). For this reason, nativity of PLWHA is considered as an antecedent characteristic.

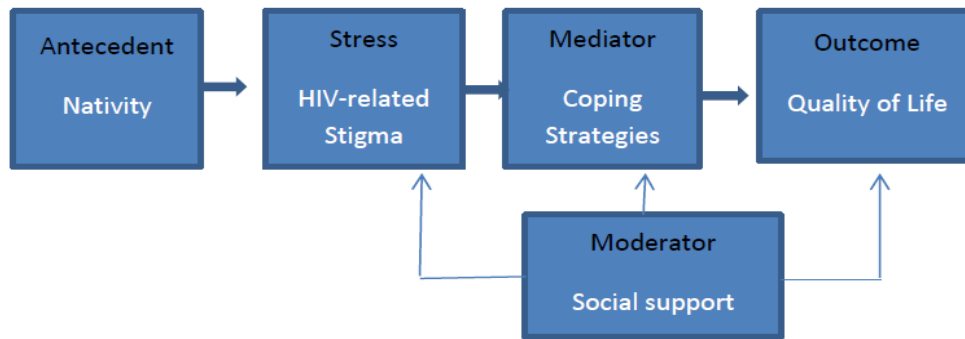


Figure 1 Conceptual Model of the Study

Perception of HIV-related Stigma as Primary Appraisal

HIV-related stigma is the prejudice and devaluing attitudes directed towards and experience by PLWHA (Goffman, 1963). The actual behaviors or actions of others toward PLWHA are referred as enacted stigma. PLWHA have their own feelings about being HIV infected and being seen differently from those who are not infected. PLWHA assess, evaluate, and internalize the devaluing attitudes regardless of the presence of enacted stigma. Perceived HIV-related stigma is considered a form of cognitive appraisal. PLWHA evaluates the gravity and threat of HIV-related stigma in their surroundings and determines how dangerous and controllable it is. PLWHA experience varying degrees of perceived stigma related to their illness (Lee, Kochman, & Sikkema, 2002). Influencing factors including the values, norms, and misperceptions about HIV in their community may also contribute to how foreign-born black PLWHA perceive stigma (Koku, 2010).

Coping with HIV-related Stigma

Researchers reported ranges of coping strategies used to cope with perceived HIV-related stigma (Kotze et al., 2013; Makoae et al., 2008; Moskowitz et al., 2009; Noh et al., 2012; Stutterheim et al., 2012b). Most literature on HIV/AIDS use broader dimensions of approach and avoidance coping. Both approach and avoidance coping were found to be associated with positive and negative health outcomes including HRQoL (Moskowitz et al., 2009), which are discussed in chapter two in detail. The way PLWHA cope with perceived HIV-related stigma is influenced by cultural beliefs and values (Makoae et al., 2008; Wolitski, Pals, Kidder, Courtenay-Quirk & Holtgrave, 2009). The focus of this study, avoidance coping in particular is correlated with negative effects including isolation and depression (Gore-Felton et al., 2006; Moskowitz et al., 2009; Vyavaharkar et al., 2010; Wolitski et al., 2009). Coping with HIV-related stigma can affect whether and how people care for themselves, their search for medical care and social support, and how well they follow the advice of the health care professionals (Dunn, Green & Roberts, 2009).

Perceived Social Support

Social support is a key factor in buffering the effect of stressors and minimizing adverse outcomes. Environments involving stigmatizing and unsupportive people often lead to non-disclosure, withdrawal from social networks and social isolation (Sayles et al., 2008). On the other hand, those who choose to seek help from others and have a good social support system have been found to deal with stigma better than those who don't have such support (Colbert, Kim, Sereika & Erlen, 2010). The possible pathways in which perceived social support influences coping with HIV-related stigma are 1) by providing opportunities to explore different

coping strategies, and 2) buffer the effect of coping strategies on the HRQoL. Perceived social support is considered a moderator of the HIV-related stigma coping process and its outcome (Wenzel et al., 2002). That is, the secondary appraisal of HIV-related stigma and its effect on the coping strategies as well as the adjustment of a person may depend, in part, on his or her perceived social support in their environment.

Health-related Quality of Life as Outcome

Researchers identified stressful life events such as HIV-related stigma as factors affecting various dimensions of HRQoL. PLWHA who do not cope well with HIV-related stigma may have poor HRQoL and vice versa. PLWHA perceptions of stigma determine how it affects the health outcome as mediated by the coping strategy they use and their perception of the adequacy of resources available to them (Holzemer et al., 2009). In conclusion, TSC help explore the relationship between HIV-related stigma, coping strategy, social support and HRQoL among native-born and foreign-born black PLWHA.

CHAPTER TWO: LITTRATURE REVIEW

This chapter provides background information on HIV-related stigma and black PLWHA in the United States. The relationships between HIV-related stigma, coping strategies, social support and health-related quality of life among black PLWHA are discussed. This chapter is organized into the following sections: (I) HIV/AIDS epidemic among Blacks in the U.S., (II) HIV-related stigma, (III) status disclosure and HIV-related stigma, (IV) coping with HIV-related stigma, (V) social support and coping with HIV-related stigma , (VI) Health-related quality of life, and (VII) HIV-related stigma & Health-related Quality of life.

HIV/AIDS Epidemic in the United States

HIV/AIDS Epidemic Among Blacks in the United States

Over the years, the HIV/AIDS epidemic in the United States has evolved from a disease of primarily white homosexuals to an increase in cases among blacks and heterosexuals. African Americans have been disproportionately affected, experiencing the highest HIV and AIDS prevalence and incidence rates. Although African Americans or blacks make up only 14% of the U.S. population in 2009, they accounted for 44% of all new HIV infections in that year. In 2009, among adolescents, African Americans/blacks accounted for 73% of diagnosed infections, and the rate of diagnosis was more than 5 times the rate for Hispanics/Latinos and nearly 23 times the rate for whites. Among young adults, African Americans/blacks accounted for 62 % of diagnosed infections, and the rate of diagnosis was nearly 4 times the rate for Hispanics/Latinos and nearly 13 times the rate for whites. Similarly, African Americans/black accounted for the highest percentage and rates among adolescents and young adults with a diagnosis of AIDS. In 2009, among adolescents, African Americans/blacks accounted for 69% of AIDS diagnoses, and

the rate was more than 4 times the rate for Hispanics/Latinos and more than 41 times the rate for whites. Among young adults, African Americans/blacks accounted for 62 % of AIDS diagnoses, and the rate was nearly 4 times the rate for Hispanics/Latinos and more than 17 times the rate for whites (CDC, 2012).

HIV/AIDS Epidemic Among Foreign-born Blacks in the United States

The United Nations reports that many of the foreign-born immigrants in the United States from HIV endemic regions have higher HIV prevalence than the native-born population (UNAIDS, 2009). Since the sub-Saharan and Caribbean regions are most hit by the HIV epidemic, it is anticipated that the HIV rates will be higher among immigrants from these regions. Even though the overall proportion of black foreign-born PLWHA is not known, a recent report indicates a significant number of black foreign-born PLWHA reside in the United States. Johnson, Hu and Dean (2010) reported that 11.2 percent of black adults and adolescents diagnosed with HIV infection in 33 states that reported this information between 2001 and 2007 were foreign-born. Furthermore, the repeal of the travel ban in 2010 is expected to draw more foreign-born individuals to the US health care system without being afraid of being deported or denied benefits of changing their residency status.

The HIV/AIDS epidemic among the foreign-born black population in the U.S. remains invisible in national HIV policies and intervention programs. This is mainly because of variation in the collection of country of birth information. Failing to account for the diverse population within black PLWHA will have implications for treatment and care of HIV infection. HIV interventions and care modules tested and used among US-born African American PLWHA may not be applicable to foreign-born black PLWHA such as African born and Caribbean PLWHA. Many research studies in public health continue to cluster black immigrants together with

African Americans despite distinct differences in immigration patterns, cultural practices, socioeconomic status, different stressors, and health status. Identifying the risk factors and burden of HIV disease within each native subgroup of black population of PLWHA in the United States is critical.

HIV-related Stigma

Defining HIV-related Stigma

A stigmatized person has an attribute that conveys a devalued social identity within a particular context (Goffman, 1963). Conceptualization of stigma evolved to include not only a cognitive phenomenon at the individual level but also a complex social process at the community level (Mahajan, Sayle & Patel, 2008). Stigma results from “a complex social process linked to competition of power and tied into existing mechanisms of dominance and exclusion” (Campbell & Deacon, 2006, p. 412). Factors such as social, economic, and political power that enable a community to identify undesirable attributes, construct stereotypes, and, ultimately, to act on the stereotypes by stigmatizing the undesired attribute are critical. The social context preceding HIV infection such as poverty and racism reinforce stigmatizing conditions (Castro & Farmer, 2005).

Stigma, fear, discrimination, homophobia, and negative perceptions about HIV are predominant among African American communities in the United States. Those challenges can in addition to lack of awareness of HIV status and socioeconomic issues associated with poverty place many more African Americans at higher risk (CDC, 2011). Since an HIV infected individual’s experience of stigma is associated with the existence of devalued attribute toward PLWHA in their community and can lead to less and less preventive measures taken by PLWHA, it is critical that management of HIV/AIDS involve helping PLWHA deal with stigma.

Stigma is conceptualized in this study as a social construction of an attribute influenced by both individual predisposition and structural factors that affect the experience of PLWHA. It is associated with perception of immoral sexual behavior and the fear of contracting the disease (Cole, 2006; Nyblade et al., 2003). Sexual behaviors considered forbidden or immoral include having multiple sex partners, homosexuality, and trading sex for money and drugs (Reidpath & Chan, 2005). Those behaviors are associated with certain groups, including gay men, intravenous drug users, prostitutes, and Haitian immigrants. Individuals who belong to one of these groups are often ostracized and considered as a source of HIV (Morrison, 2006). Even with better understanding of how one acquires HIV infection, people are still afraid of contracting HIV through causal contact. Individuals infected with HIV are viewed as more responsible for their health consequences, more dangerous, more deserving of infection, and to be avoided compared to people with other infections (Skeleton, 2006).

Prevalence of HIV-related Stigma in the United States

Prevalence and trends of HIV-related stigma from 1991 to 1999 indicate that HIV is a highly stigmatizing condition in the U.S. (Herek et al., 2002). Herek and colleagues (2002) analyzed data from national surveys of U.S. adults 1997-1999 and compared the result with 1991 survey. They found a decline in support for punitive policies toward PLWHA, persistent negative feeling toward PLWHAs and a significant increase in the number of people who believe that “people who got AIDS through sex and drug use have gotten what they deserve”. Although overt expressions of stigma appear to have reduced from 1991 to 1997, more covert forms of stigma persist in general population resulting in avoidance and mistreatment of PLWHA.

A recent telephone survey among a nationally representative sample of 2554 adults in 2009, Kaiser Family foundation found a notable share of the respondents say they would be uncomfortable with an HIV-positive coworker (23 %), child's teacher (35%), and roommate (42%). Half of those respondents (51%) reported they would be uncomfortable having their food prepared by someone who is HIV positive. In general these findings indicated that negative stereotype continues to be pervasive and features prominently in the lives of PLWHA in the United States (Kaiser Family Foundation, 2009).

Because of their social and cultural backgrounds, foreign-born PLWHA are more vulnerable to HIV-related stigma than native-born PLWHA and its impact may be worse for foreign-born PLWHA. On the one hand, foreign-born PLWHA are forced to contend with layering stigma as they possess devaluing identities related to their immigration (Darrow, Montanea & Gladwin, 2009). On the other hand, they suffer more intense HIV-related stigma as the number of devaluing attributes toward HIV infection may be higher in the smaller community of their own origin. In a recent study among minorities, respondents who claimed their country of origin was not the United States were more likely to indicate two or more stigmatizing attitudes toward PLWHA than respondents who claimed the U.S. as their country of origin (Reo-Ellis et al, 2008).

Factors Associated with HIV-related Stigma

Lack of knowledge, misinformation, and myths about HIV transmission contribute to HIV-related stigma. Individuals who have more HIV knowledge were less worried and less likely to stigmatize PLWHA than those with less knowledge (Des Jarlais, Galea, Tracy, Tross & Vlahov, 2006; Visser, Makin, Vandormael, Sikkema& Forsyth, 2009). However, knowledge or

awareness of HIV has not always been related with lesser HIV-related stigma depending on cultural and religious norms of the study population. For instance, Beyene (2000) found that Ethiopian and Eritrean immigrants were afraid to discuss HIV with their friends and deny their personal HIV risk behaviors even though their level of HIV awareness was high.

Parker and Aggleton (2003) suggested sexuality, gender, race/ethnicity, and class influence HIV-related stigma. For example, PLWHAs who reported higher over all internalized stigma were members of racial/ethnic minorities, had low levels of income or education, were not native English speakers, and heterosexual (Sayles et al., 2008). A meta-analysis of 24 articles conducted in North America reported that HIV-related stigma was significantly and negatively correlated with age and income. However, correlations between HIV-related stigma and ethnicity were inconsistent. Only two articles reported the relationship between ethnicity and HIV-related stigma with opposite findings; one study found higher levels of stigma among non-whites while another study found higher levels of stigma among whites (Logie & Gadalla, 2009).

HIV-related Stigma and Foreign-born Black Population

The nature of HIV-related stigma becomes complicated when considered in light of different cultural values and background (Parker & Aggleton, 2003). HIV-related stigma has been the major hindrance to HIV prevention and treatment in regions hardest hit by HIV/AIDS such as sub-Saharan Africa and the Caribbean. For instance, 75% of HIV-positive respondents had experienced stigma in Kenya (Odindo & Mwanthi, 2008). Interviews with organizations and individuals who participate in the fight against HIV/AIDS in those regions also reveal the severity of HIV-related stigma. Non-governmental organization directors in 29 African countries cited HIV-related stigma after funding when they were asked to describe the most important

challenges (Benotsch et al., 2008). Similarly, interviews of policymakers and activists in the Dominican Republic and Guyana highlighted stigma and discrimination as obstacles to HIV/AIDS prevention efforts (Amnesty International, 2006).

The severity and complexity of HIV-related stigma in foreign-born persons might experience in their country of origin has a serious impact when they immigrate to other countries (Dodds, 2006; Elford, Ibrahim, Bukutu & Anderson, 2008; Lawson et al., 2006; Loufty et al., 2012; Prost, 2005). Foreign-born individuals bring their HIV/AIDS knowledge, attitudes, and beliefs with them and their perceptions of HIV/AIDS depend on their background and culture. Studies have shown that cultural, socioeconomic and religious differences exist within foreign-born black communities (Sheldin et al., 2006) that might have implications on their risk for HIV infection. Sexual behavior often is grounded to cultural perceptions, norms, and gender expectations within one's culture. For example, HIV-related stigma is so strong in Ethiopian and Eritreans communities that PLWHAs from those countries literally hide from other Ethiopians and Eritreans who come to the clinic for the same reason (Beyene, 2000). Caribbean native mothers preferred their daughters not have friends with HIV/AIDS and not go to their HIV infected friend's house (Archibald, 2010).

Likewise, foreign-born PLWHA's perception and experience of HIV stigma depend on the meaning of and assumptions held about HIV and PLWHA in their countries of origin or the culture. Many foreign-born black HIV infected individuals face not only HIV-related stigma and discrimination within their own small community; they also have barriers such as difficulty accessing HIV care and other immigration related stressors from their host community (Read et al., 2005; Page, Goldbaum, Kent, & Buskin, 2009). As Koku (2010) described in his research among African PLWHA living in the U.S., the participants' experiences and response to

stigmatization is shaped mainly by cultural/religious assumptions and perceptions about HIV learned in their home countries and the western media's construction of HIV. African-born PLWHA in Koku's study (2010) traced the denial and internalized stigma to the fact that HIV is a taboo subject, a curse for the past immoral acts, and other beliefs common in their African origin. Despite the change in the U.S. black immigrant population and change in policy, relatively few studies have focused primarily on black foreign-born and native-born differentials on HIV/AIDS prevalence and risk factors.

Impact of HIV-related Stigma

Fear of stigma discourages PLWHAs from seeking health care and social resources that are essential for effective management of HIV disease. They avoid settings such as community centers, support groups, or assistant programs because they fear being identified and stigmatized (Koku, 2010; Othieno, 2007). HIV-related stigma interferes with HIV infected individual's intention and ability to access care services. Levy and his colleagues assessed factors in the delayed presentation of HIV patients among a sample in which 28% were immigrants. The majority of the immigrants (78.7 %) in this study were Hispanic. Compared to U.S. born patients, immigrants including Hispanic and non-Hispanic blacks presented with lower CD4+ counts, were more likely to have opportunistic infections and more likely to be hospitalized at initial HIV diagnosis. They found only immigrant status significantly and independently associated with delayed HIV presentation (Levy et al., 2007).

Furthermore, HIV-related stigma from health care providers and institutions presents a barrier to access and stay in care. Kinsler and colleagues (2007) examined the effect of stigmatizing attitudes of health care providers on PLWHA access to care. Their result revealed

that stigma perceived by low-income PLWHA was significantly associated with low access of care after controlling for socio-demographic characteristics and most recent CD4 counts.

Foreign-born PLWHA may face care provider's stigmatizing attitude toward their immigration status or country of origin in addition to being HIV infected. In a recent study, African-born PLWHA also indicated health care provider's negative attitudes and disrespect for their language difficulties and associated their HIV status with the countries of origin (Koku, 2010).

Additionally, stigma has been persistently found to be negatively associated with the use of and compliance with antiretroviral therapy (Rao et al., 2007, Vunable , Carey, Blair, & Littlewood, 2006; Wolitski et al.,2009). Fear of disclosure associated with purchasing, carrying and taking HIV medicine and subsequent HIV-related stigma negatively impact medication adherence among PLWHA.

Internalization of stigma causes self-blame, feeling of shame and guilt of being HIV infected which can lead to isolation and withdrawal among HIV-infected population. Results of a cross-sectional study examining HIV-related stigma and depression among HIV-infected African American women living in the rural areas of the south-eastern United States indicated that perceived and internalized HIV-related stigma variables were significantly and positively correlated with depression (Vyavaharker et al., 2010). PLWHA who perceive and experience HIV-related stigma most likely suffer from poor psychological wellbeing, lower social support, greater HIV symptom and undesirable health outcomes (Kalichman et al, 2009; Holzemer et al, 2009 ; Nyblade , 2006). Logie and Gadalla (2009) performed a meta-analysis and examined the relationship of HIV-related stigma with physical and health characteristics. Twenty four studies conducted in North America and published in peer review journals were included. Despite substantial variability in the ways researcher's measure participants' HIV-related stigma as well

as physical, emotional, and mental health, Logie and Gadalla found that high stigma level was consistently and significantly associated with low social support, poor physical health, poor mental health, age and income. Researchers also identified a positive association between HIV-related stigma and poor quality of life among PLWHAs. A recent study among an international sample of 729 PLWHA including those from Sub-Saharan Africa and Caribbean found that perceived HIV stigma had a significant negative impact on HRQoL (Holzemer et al., 2009).

Status Disclosure and HIV-related Stigma

PLWHA who perceived other's negative attitude, low self-esteem and ashamed of being HIV-infected disclose their positive status to fewer individuals (Aggleston & Parker, 2002, Vance, 2006). Disclosure is defined as the giving out of information, which might commonly be kept secret. UNCEF/WHO defined disclosure of HIV status as the act of informing any individual or organization, of the serostatus (WHO/UNAIDS, 1999). Both disclosing and concealing HIV infection to others could have either positive (better support) or negative (violence, stigma & discrimination) effects or both (Lee & Craft, 2002). On one hand, disclosing HIV-positive status will help PLWHA to seek needed medical care and social support which improve overall health; however, on the other hand, it may expose PLWHA to rejection and discrimination by others including health care professionals.

Some may argue that availability of advanced and optimal HIV infection management such as antiretroviral therapy (ART) have made it possible for PLWHA to conceal their illness and to 'pass' as uninfected through enabling PLWHA to remain relatively healthy for longer periods. Yet, they may suffer the psychological toll of having to maintain a secret identity and possibly forgo needed support (Koku, 2010). For instance, evidence from a study examining patterns of disclosure before and after the introduction of highly active antiretroviral therapy

showed that internalized stigma remains a prominent barrier to disclosure and a considerable source of stress among HIV infected women. In fact, HIV infected women in the ART era were significantly more likely than women in the pre-ART era to report stress from stigma and disclosure, to view HIV as having caused them harm (Makoae et al., 2009; Seigal & Schrimshaw, 2005).

Disclosure is a complex phenomenon that depends on several factors including fear, stigma and one's social relationships (Bairan et al., 2007). HIV infected African and Afro-Caribbean in the Netherlands stated fear of stigmatization, previous negative experience with disclosure, having observed the stigmatization of other PLWHA, shame, desire to protect children and family, and the belief that one's HIV status is a private matter as a reasons for not disclosing their status (Stutterheim et al., 2011). The choice to disclose status should be PLWHA's decision; however, inadvertent disclosure might occur when clues, such as taking ART, being seen in HIV clinic, are noticed by others. Fear of such uncontrolled status disclosure is directly associated with delay in testing and entry to care after a HIV positive diagnosis. In one study, African born PLWHA reported that they avoid seeking health care or support they need, discontinue their HIV care; perhaps, choose to travel to nearby town for care so they can avoid being seen in the HIV clinic (Koku, 2010). Another study found that cultural experts from African communities strongly felt that African-born PLWHA would not access service if service sites were located in geographical areas that are inhabited predominantly by members of their own communities. However, African-born PLWHA in the same study didn't agree with this assertion and felt that location didn't matter to them (Othieno, 2007).

Not disclosing one's HIV status can lead to social isolation and lack of social support (Vyavaharker et al., 2010; Ware, Wyatt & Tugenberg, 2005). Social isolation and lack of support

often cause adverse outcomes such as depression and anxiety (Emlet, 2007, Prachakul, Grant, & Keltner, 2007, Simbayi et al, 2007). In one study, HIV infected women view HIV as having caused them harm and report more use of maladaptive forms of coping such as isolation and being more depressed (Seigal & Schrimshaw, 2005). A study examining the actual impact of HIV status disclosure on the lives of Asian/Pacific Islander and African-born PLWHA found that although disclosure is stressful due to perceived stigma, it eventually can be liberating and lead to less stressful and more productive life as well as improved wellbeing (Chin & Krosen, 1999; Koku, 2010).

Coping

Coping with HIV-related Stigma

Coping is a cognitive or behavioral response to a situation appraised as stressful. Fear of being identified as HIV infected, stigmatized and discriminated are potential stressors associated with HIV-related stigma. As the numbers of years PLWHA are living increase, so does the number of and types of stresses they have to cope with. Advance in care and treatment of HIV also change the coping strategies PLWHA choose to handle stressors. For example, strategies used to hide HIV medication when one is required to take four times a day may be different from the strategy used when it changes to once or twice a day. The constant changes in coping process make coping research and the measurement of coping complex.

Coping with HIV-related stigma can affect whether and how people care for themselves, their search for medical care and social support, and how well they follow the advice of the professionals (Dunn, et al., 2009). PLWHAs who do not cope well with HIV-related stigma may have poor quality of life and health which in turn worsens their stress. Those who cope well may achieve a higher quality and healthier life that change their perception of their disease and way of

life. PLWHA cope with HIV-related stigma in a variety of ways. Some of them choose avoidance and psychological disengagement which is associated with poor psychological well-being (Moskowitz et al., 2009), and isolation and increasing symptoms of depression (Gore-Felton et al, 2006; Vyavaharkar et al, 2010), which is well known to affect their quality of life (Cohen et al , 2002). Others who choose to disclose status, seek help from others, and have a good social support system are able to deal with stigma associated problems better than those who don't have such support (Colbert et al, 2010).

Moskowitz et al. (2009) conducted a meta-analysis to determine which types of coping are related to psychological and physical wellbeing among PLWHA. Sixty three articles with a total sample of 15,490 participants were included in this analysis. The sample for selected studies had to be diagnosed as HIV positive 18 years and older, and from United States, Canada, Europe, or Australia/New Zealand. They categorized type of coping using the coping strategies from the Ways of Coping (Folkman & Lazarus, 1988) and the COPE (Carver , Scheier, & Weintraub, 1989). Eighteen types of coping were analyzed. Study outcomes were grouped into positive affect, negative affect, health behaviors and physical health. Positive affect included quality of life, life satisfaction, and positive mood. Negative affect included depression, mood disturbance, emotional distress, anxiety, anger, perceived stress, hopelessness and traumatization. Physical health included mortality, disease severity and somatic symptoms, viral load, physical health, CD4 count, survival time, and cortisone level. Direct Action, Positive Reappraisal, and Spirituality were associated with higher levels of positive affect; Alcohol/Drug Disengagement, Behavioral Disengagement, Escape/Avoidance, and Social Isolation were associated with lower positive affect. Acceptance, Direct Action, Fighting Spirit, Planning, Positive Reappraisal, and Seeking Social Support were significantly associated with lower negative affect. Self- Blame,

Alcohol/Drug Disengagement, Behavioral Disengagement, Confrontive, Distancing, Escape/Avoidance, Hopelessness, Rumination, Self-Controlling, Social Isolation, and Venting were associated with higher negative affect. Direct Action and Positive Reappraisal were associated with better physical health. Behavioral Disengagement, Distancing, and Venting were associated with poorer physical health (Moskowitz et al., 2009).

Moskowitz and colleagues (2009) also classified types of coping into Approach and Avoidance, and re-ran the meta-analyses for each of the four outcomes. They classified Acceptance, Confrontive, Direct Action, Fighting Spirit, Planning, Positive Reappraisal, Seeking Social Support, Self-Blame, Self-Controlling, and Spirituality as Approach. Alcohol/Drug Disengagement, Behavioral Disengagement, Distancing, Escape/Avoidance, and Social Isolation were classified as Avoidance. Approach coping was significantly associated with increased positive affect, decreased negative affect, and better physical health. Avoidance coping was associated with lower positive affect, higher negative affect, and poorer physical health.

Coping with HIV-related Stigma and Foreign-born Black PLWHA

Not only the perceived HIV-related stigma, but also the way individuals cope with it, is influenced by cultural beliefs and values (Makoae et al., 2009; Wolitski, et al., 2009). As in the case of HIV-related stigma, there are few studies published about the coping strategies of foreign-born black PLWHA in the U.S. or North America. In his qualitative study, Koku (2010) his African-born PLWHA participants chose to confront and resist stigma through strategies such as keeping their status secret. Hiding their illness is very common in this group. In some cases where they chose to disclose, they were very selective and strategic. Some of them also mentioned public disclosure to normalize life with HIV.

Recent studies from Canada (Noh et al., 2012), Netherlands (Stutterheim et al., 2012), and UK (Dibb & Kamalesh, 2012) assessed coping strategies among foreign-born black PLWHA in their respective countries. A study among 259 adult HIV-infected immigrants, of whom 70% were black, in Canada assessed adaptive and maladaptive coping strategies and their relationship with depression and HIV symptom. They found that adaptive coping related to lower depressive symptoms while maladaptive coping related to higher depressive symptom (Noh et al., 2012). Similarly, a longitudinal study among HIV-infected pregnant women in South Africa found association between increased avoidant coping and increased internalized stigma, increased depression, and lower levels of self-esteem (Kotze et al., 2013).

Another study among African and Afro-Caribbean PLWHA and HIV-negative African and Caribbean adults who live in the Netherlands assessed coping and its relation to HIV-related stigma. According to Stutterheim and her colleagues, African and Afro-Caribbean PLWHA employed both emotion and problem-focused coping strategies to deal with HIV-related stigma. The strategies categorized as emotional and problem-focused in Stutterheim et al.'s study do not align with the classification of coping as approach and avoidance reported in other coping articles cited here. However, it provides evidence that like in other racial groups of PLWHA, foreign-born black PLWHA used several coping strategies to mitigate the effect of HIV-related stigma (Stutterheim et al., 2012).

Social Support

Perceived Social Support and HIV-related Stigma

Social support can be defined in terms of its structural and functional aspect. The structural aspect is one's social network and the functional aspect is the positive interaction and supportive actions within the social network. Social support can also be defined as perceived

and received. Perceived social support is a person's perception of his or her social network and availability of social provisions whereas received social support is the actual social support received by the person. Several researchers have defined and measured the concept of social support in numerous ways. In this study, the actual use of social support such as obtaining social support is considered a coping strategy while perceived social support is the moderator of HIV-related stigma coping process and its outcome. Perceived social support is a person's perception of his or her social network and availability of social provisions. Social provisions are the functional aspect of one's social network which includes the positive interaction and relationship between a person and his/her social network.

Effects of social support have been studied extensively among PLWHA (Smith, Rossetto & Peterson, 2008; Vyavaharkar et al, 2010). It is an essential component of daily survival. The dominant theory is that social support provides a buffering effect against the adverse effects of stress (Wills & Shinar, 2000). Wenzel and her colleagues (2002) consider the individual differences in perceived social support a moderator of the impact of stress on the coping process and outcome. First, it can serve as a coping resource that directly affects one's appraisal of stress. Smith, Rossetto & Peterson (2008) did meta-analysis of 21 studies, of which 17 were conducted in the U.S. They reported a significant negative correlation between stigma and social support. Second, it provides opportunities to explore different coping options and influence the coping strategies used that in turn influence the adaptation outcome. For example, greater social support was one of the significant predictors of life satisfaction and health-related quality of life among PLWHA. Satisfaction and perceived adequacy of social support was higher among PLWHA's who have no clinical depression, higher quality of life and adhere to their HIV medication (Safren, Radomsky, Otto & Salomon, 2002; Vyavaharker et al., 2010).

Some researchers compared the different impact of perceived and actual social support. Perceived social support was found to be very important especially among HIV infected women. A study examining the perceived social support and psychological distress among HIV-infected women reported that lack of perceived social support a significant predictor of psychological distress (Hudson et al., 2001). Hudson and colleagues also reported that lack of perceived social support was associated with psychological distress more so than stressors of ethnicity. Other studies examined the relationship between perceived and actual social support with mental health outcomes such as depression among PLWHA (McDowell & Serovich, 2007; Serovich et al., 2001). One study found that only perceived social support predicted depressive symptoms (McDowell & Serovich, 2007) while the other study found perceived social support to be correlated with all mental health outcomes such as depression, loneliness, anxiety, and stress than actual support (Serovich et al., 2001).

Social support was also reported to be directly related with progression to AIDS which in turn affected the HRQoL. Leserman et al. (1999) conducted a longitudinal study and assessed the effects of stress, depressive symptoms, and social support on disease progression among asymptomatic PLWHA. They found that faster progression to AIDS was significantly associated with low social support. The probability of getting AIDS at the fifth year of the study among those who had low social support was about 2.7 times higher compare with those who had higher social support (Leserman et al., 1999).

Perceived Social Support and Foreign-born Black PLWHA

Perceived HIV-related stigma often impairs PLWHA's social relationship. However, the effect of social support and the process by which it affects the relationship between HIV-related

stigma, coping and health outcomes is not clear. Even though the need for social support might vary from person to person and from time to time, it is considered essential for adequate personal adjustment. Absence of social support leads to distress. Although many studies reported on social support and its effect on the lives of PLWHA, there still is a limited understanding of the mechanisms and processes through which it may exert its effect among foreign-born PLWHA. For instance, researchers found the western concept of emotional support is unfamiliar to African PLWHA. As a frustrated participant who had been in and out of care was quoted “All we do is eat, talk, and light candle!” (Othieno, 2007 *pg* 180). In a recent study among 259 adult HIV-infected immigrants in Canada, of whom 70% were black, participants reported that perceived social support has a significant negative relationship with depressive symptom (Noh et al., 2012). This study fills a gap in the need for understanding foreign-born PLWHAs perspective.

Furthermore, Layne and his colleagues (2009) assert that studies do not account for the broad array of the source, types and functions of social support. Assessing social support from multiple sources in the social network is critical in the understanding of its impact in populations like immigrants. As foreign-born individuals acculturate and create several social interactions within their own ethnic community as well as to the hosting community, their perceived level of social support may vary across distinct immigrant groups with which they interact. Thus, foreign-born PLWHA fear of being stigmatized and losing their social support if their HIV status becomes known may be higher in the context of their own ethnic community than the general community if the stigma attached to HIV infection is higher in their ethnic community of their own origin.

Health-related Quality of Life

Defining Health-related Quality of Life

The World Health Organization (2006) defines health as a state of complete physical, mental, and social well-being and not merely the absence of infirmity and disease. Researchers and clinicians have focused on health outcomes that are physically or laboratory measured such as symptoms, viral load and efficacy of treatment. Biomedical measures, however, do not reflect how the affected individual feels and functions in daily life. Quality of life (QoL) is defined as the individual's self-evaluation of their well being and considers physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of the environment (The WHOQOL Group, 1998). QoL is a multidimensional concept that encompasses several domains of life, such as achievements (personal and economic), satisfaction (life and job), and happiness and health (Bowling, 2005). Kaplan and Bush (1982) propose the use of the term Health Related Quality of Life (HRQoL) to distinguish health effect from other factors influencing the subject's perception, such as job satisfaction. HRQoL focuses on those aspects of overall QoL that can be clearly shown to affect health (CDC, 2000). Thus, HRQoL refers to how well a person functions and to his or her perceptions of well-being in the physical, mental, and social domains of life in this study. Dimensions of HRQoL commonly measured include physical health and functioning, mental health and functioning, social and role functioning, and general well-being (Coons, 2005).

Wilson and Cleary (1995) presented a conceptual framework illustrating hypothesized causal relationships among various domains of health outcome. They suggested a linear

continuum process that starts with a biological variable (e.g., HIV infection). The biological variable then predicts symptom status (e.g., fatigue), which in turn predicts functional status (e.g., physical and social functioning), and end with general health perceptions and overall HRQoL. Recent studies suggest that variables external to the disease process such as HIV-related stigma are associated with HRQoL (Aranda-Naranjo, 2004). Increased longevity is one of the benefits of antiretroviral therapy. However, in the absence of a consistently high HRQoL, the extension of life is meaningless. Grossman, Sullivan, and Wu (2003) pointed out that many PLWHA report HRQoL that is lower than both the general population and persons with other chronic illnesses, such as cancer or depression. Thus, HRQoL has become an important endpoint measure to assess the burden of HIV/AIDS, changes in health, and effects of treatment and interventions (Mrus et al., 2006). Understanding factors affecting HRQoL such as HIV-related stigma among PLWHA is important to deliver effective and efficient interventions to achieve optimal HRQoL.

Factors Associated with Health-related Quality of Life

HRQoL can be affected by personal (e.g., poverty), biological (e.g., symptoms) and psychosocial factors (e.g., psychiatric symptoms, stigma, and poor social support). Campsmith, Nakashima, and Davidson (2003) revealed that, among PLWHA, lower scores on the overall health dimension of HRQoL were associated with being older, being female, being black or Hispanic, having been infected via intravenous drug use, having a low CD4 count, having less than 12 years of education, lacking private health insurance, and having a low income. Perez et al. (2005) reported that among PLWHA, better physical and mental HRQoL is associated with being female, being employed, the absence of mental illness, receiving social support, having a stable partner, and not being an intravenous drug user.

Biological factors, including the disease state, HIV symptoms, treatments, and co-morbidity have been associated with HRQoL (Davis, 2004; Hansen, Vaughan, Cavanaugh, & Connell, 2009; Holzemer et al., 2009; Spirig, Moody, Battagay, & De, 2005). The psychosocial stress that comes along with the illness affects how well a person functions and interacts with others. Portillo et al. (2005) found that individual characteristics, environment, physiological factors, symptom status, functional status, and general health perceptions contributed significantly to HRQoL in an ethnic minority sample of which 50 % were African Americans. Stress such as HIV-related stigma, low self-esteem, shame, depression, lower social support, and medication non-adherence are also known to contribute to poorer HRQoL. A study among African American men reported that factors such as personalized stigma, negative self-image, disclosure concerns, and public attitudes were inversely associated with life satisfaction and accounted for 40.2 % of variance in life satisfaction after adjusting for socio-demographic variables (Buseh et al., 2006).

Health-related Quality of Life and Foreign-born Population

As Aranda-Naranjo (2004) states “with a greater percentage of HIV positive patients possessing a range of cultural beliefs and values, it is essential for HIV care providers to understand that for the socially marginalized patients, the complexity of psychosocial factors, in addition to the differences in lifestyle, cultural beliefs, and ethnic experiences, affect quality of life.” Social, cultural, and economic factors play a significant role in the overall health status of foreign-born populations. Beyene (2000) provided a long list of barriers to HIV prevention and care among the general population of African immigrants in California such as stigma, the isolation of HIV-positive individuals, cultural beliefs, linguistic barriers to treatment and access to health care, lack of discussion about HIV and sexual matters, denial about HIV risks, fear of

HIV testing, and HIV risk behaviors. Likewise, foreign-born PLWHA face all those barriers to optimal care that exist in their immigrant community.

Comparative studies on other chronic illnesses, however, reported that foreign-born populations in general have better physical health than native populations (Read, Emerson, & Tarlov, 2005). Foreign-born people exhibit longer life expectancies, lower overall mortality rates, and lower prevalence of conditions such as hypertension, high cholesterol, cardiovascular disease, and asthma compared with native-born counterparts (Singh et al., 2006). Several theories are referred in an explanation about why foreign-born people exhibit better health in the U.S. than native-born people. First, immigration often is not a random process and those who immigrate are healthier due to their specific characteristics that are favorable to positive health outcomes such as younger age, better levels of educational attainment, and correspondingly higher socioeconomic status compared to those they leave behind and compared to native-born individuals. Second, the health selection through screening from the medical screening done before entry may lead to healthier individuals to immigrate to U.S. (Jasso, Rosenzweig & Smith, 2005). Third, the salmon bias which is the situation where those immigrants who are ill return to their home countries, resulting in a healthier group remaining in the U.S. (Palloni & Arias, 2004). Fourth, maintenance of healthy behavior associated with a traditional lifestyle such as healthier eating habits also mentioned in diet and nutrition related research (Goel, McCarthy, Phillips, & Wee, 2004). Foreign-born population, however, do not exhibit better health for all chronic illnesses and disease situations. For example, compared to native born, immigrants experience higher mortality due to infectious diseases such as tuberculosis. In 2009, the percentage of TB cases occurring in foreign-born persons was 59% of the national total in the U.S. (CDC, 2010).

Foreign-born PLWHAs, in particular, face multiple influences from their infection, such as stigma, lack of social support, depression, substance abuse, domestic violence, cultural beliefs, legal status concerns, fear of the American health system, and linguistic difficulties, which can affect their HRQoL (Koku, 2010; Shedlin et al., 2006). Thus, they may have a poorer HRQoL compared to their native-born counterparts. Conservative values and social norms in their communities favor stigmatization, making most of them reluctant to disclose their HIV infection status, which further alienates them from much needed social support (Hudson, Lee, Miramontes, & Portillo, 2001). A recent study confirmed a much higher virological failure rate among immigrants despite no difference in adherence between immigrant and non-immigrant patients (Nellen et al., 2009). The authors of this article posited unstructured treatment interruptions as a likely explanation for their findings. In addition, foreign-born PLWHA face stigma related to their immigration. Bianchi and his colleagues (2004) found that socio-cultural factors including acculturation to the U.S. and discrimination based on race or ethnicity negatively influenced active coping, which in turn impacted the health behaviors of HIV-infected Latino gay men who are from Mexico, Central America, South America and the Caribbean.

Relationships of HIV-related Stigma and Health-related Quality of Life

Studies on HIV-related stigma target HIV uninfected individuals and lack consideration of the mechanisms through which HIV-related stigma impacts PLWHA (Earnshaw & Chaudoir, 2009). Holzemer and his colleagues (2007) developed a conceptual model of perceived HIV/AIDS-related stigma and its impact on PLWHA, which identifies HRQoL as one of the outcomes of HIV-related stigma. Fear of prejudice and judgment from others influence the way PLWHA feel about the infection and how they cope with the disease. Often times, PLWHA

internalize the devaluing label attached to their disease that leads to the guilt, self-blame, and shame that ultimately result in disempowerment. A study among African-American men found that those who perceived a higher level of stigma felt negative self-image and reported less satisfaction with their life (Buseh et al., 2006). Negative self-image not only causes coping difficulties but also leads to inadequate self-care in conjunction with other factors such as disease stage (Vanable et al., 2006).

Internalized stigma is also associated with limited functioning (Wolitski et al., 2009). For instance, limited daily functioning was predicted by stigma, fatalism, employment status, and stage of disease among sample of HIV-positive women, 82% of which were African American, in Georgia (Sowell et al., 1997). Another study among HIV-infected adults, of which 69% were African Americans/blacks, with a history of childhood sexual abuse revealed that the HIV-related, but not sexual abuse-related, shame remained a significant predictor of reduced HRQoL after controlling for demographic and clinical factors (Persons, Kirshaw, Sikkema & Hansen, 2010).

The other major association between HIV-related stigma and HRQoL is related to PLWHA's decision about status disclosure. PLWHA assess and evaluate the possible consequences of HIV-related stigma and determine their next action. PLWHA who perceive others' negative attitude may refrain from disclosing their positive status and accessing health care (Swendeman et al., 2006). Even though limiting disclosure might be considered as protective against potential stigmatizing experiences, it may lead to social isolation (Ware et al., 2005) and poor mental health (Vyavaharkar et al., 2010). Levy and his colleagues (2007) found only immigration status to be significantly associated with delayed presentation in a sample of PLWHA attending a public AIDS program. Similarly, Wolitski et al. (2009) reported the

association between perceived external stigma and recent non-adherence to HIV treatment and decreased HIV disclosure to social network members. In general, the effects of HIV-related stigma such as negative feeling, disclosure concern, social isolation, and psychological problems lead to poor access to care and poor antiretroviral treatment adherence which in turn result in poorer health outcomes (Dunn et al., 2009; Sayles et al., 2009).

A recent study among an international sample of 729 people living with HIV infection found that perceived HIV stigma had a significant negative impact upon HRQoL (Holzemer et al., 2009). Most of the subjects were residents of U.S. and Puerto Rico with only 15.4% residing in Africa. The subjects from Africa reported significantly fewer HIV symptoms than the rest of the group, where as the Hispanic subjects reported significantly more HIV stigma than African subjects. The researchers suggested that Hispanics in this study constitute a distinct ethnic group that experiences higher stigma and requires culturally appropriate stigma reduction intervention. The percentages of those Hispanic subjects who were immigrants were not reported in this study. The question emerging from these findings that needs further study is whether HIV-infected Africans' experiences would be different if they relocate to the U.S. The proposed study will explore this question.

CHAPTER THREE: METHODOLOGY

This chapter presents a discussion of methodologies employed to answer the research questions and related hypothesis generated from the critical review of the literature pertaining to HIV-related stigma, coping strategies, social support and health-related quality of life among black people living with HIV/AIDS (PLWHA). Core methodologies in the conduct of the research such as measurement, sampling, human subject protection, and the statistical analytic strategies are addressed.

Design

A cross-sectional descriptive design was used to examine the relationships between perceived HIV-related stigma, coping strategies, perceived social support and Health-related Quality of Life in a sample of 37 foreign-born and 63 native-born black people living with HIV/AIDS (PLWHA). The term “foreign-born” referred to individuals who were born outside of the U.S. or who were not a U.S. citizen at birth such as legal immigrants (i.e., naturalized citizens or “green card” holders), legal non-immigrants (e.g. foreign students), refugees, asylees and undocumented individuals. The term “native-born” referred to anyone who was born in the United States, Puerto Rico, and a U.S. Island Area.

Participants were recruited from the DeKalb County Board of Health Ryan White Early Care Clinic (RWECC) between August and November, 2012. DeKalb County Board of Health RWECC is an outpatient clinic located in metropolitan Atlanta, Georgia and specializing in the primary medical and dental care of HIV-infected individuals and offering mental health, substance abuse treatment, prevention and support services for HIV-infected and affected individuals. This clinic is the primary provider of HIV services in the DeKalb County, Georgia. Eligibility to enroll at the RWECC includes CD4 count higher than 200 cells/ μ l. Some

individuals may be kept in the RWECC with CD4 count lower than 200 cells/ μ l to maintain continuity of care. For example, an individual, who is on tuberculosis regimen through the DeKalb County Board of Health tuberculosis clinic and has a slight decreased CD4 count, may continue care in RWECC based on the decision of tuberculosis and HIV physicians. At the end of October 2011, a total of 736 PLWHA enrolled for service, of which 598 (81%) were black or African American, 69% were male and 29% were female. The percentage of foreign-born patient enrolled at RWECC is unknown at this moment because this information is not collected.

Population, Sample, Sample Size and Inclusion Criteria

The sampling frame for the study included all black/African American PLWHA who received service at RWECC between August and November, 2012. A convenient sample composed of 100 participants was used in this study. Of the 100 participants recruited, 37 were foreign-born and 55 were women (including three male to female transgenders). The sample size of 100 achieve 80 % statistical power to detect R-Squared 0.12 attributed to 5 independent variable (s) using an F-test with a significant level (alpha) of 0.05. The statistical power test was adjusted for an additional 3 independent variables(s) with an R-Squared of 0.001. The inclusion criteria were: 1) infected with HIV 2) 18 years of age or older, 3) identified self as black or Black 4) able to speak and understand English, 5) mentally competent as determined by a health care providers and 6) completed informed consent.

Recruitment and Procedure

The study was approved by the Institutional Review Boards (IRB) of Emory University and the Georgia Department of Public Health. After IRB approval, the principal investigator (PI) presented and discussed the research protocol with the RWECC providers, including medical

doctors, nurses, social workers and case managers. Providers agreed to speak to their eligible patients about participating. Flyers were posted in the waiting room and examination rooms. Patients, willing to participate and who meeting inclusion criteria, were briefed about the study and signed IRB approved consent form. Participants received a copy of signed or blank consent form based on their choice. Most of the participants opted for the blank form. Two trained research assistants, in addition to the PI, interviewed participants using structured questionnaires. All data collection took place in a private room/office inside RWECC and interviews were conducted in English. The PI evaluated completed questionnaires to make sure all questions and responses were completed at the end of each interview. Participants who completed the interview were compensated with \$15 for their time. Participants who choose to withdraw from the study were compensated with \$10 for their time regardless of the number of items completed; however there were no withdrawals.

Study Instruments

The main dependent variable is mental health summary of HRQoL and the main independent variables are nativity, perceived HIV-related stigma, coping strategies and perceived social support. Socio-demographic variables controlled for because of their significant correlation with the dependent variable (mental health summary of HRQoL) were voluntary disclosure of HIV status to at least one person and number of years since tested HIV positive. Statistical analysis was conducted using SPSS 20.0 statistical software package. The questionnaires used to interview participants are contained in the Appendix. The questionnaire included specific instructions to the interviewers regarding the manner in which it should be administered. All interviewers were trained to follow the interview script without deviation and provide prompts only where indicated in the interview protocol. The following measures were

used to assess the dependent variable and the independent variables. The internal consistency reliabilities for the study instruments with the exception of SF12v2 scale are summarized in Table 1.

Socio-demographic Measure

A structured questionnaire designed for specifically for this study to collect demographic information; age, gender, sexual orientation, race/ethnicity, nativity, religion, educational level, marital status, employment status, income, number of children, living arrangements, years since HIV diagnosis, year first started ART, diagnosis with AIDS, smoking, and recent CD4 count.

Multidimensional Measure of Internalized HIV Stigma Scale

Perceived level of HIV-related Stigma was measured using a 28-item multidimensional measure of internalized HIV stigma scale. This scale was developed to measure individual's perception and experience of internalized HIV stigma in four areas: stereotypes, disclosure concerns, social relationships, and self-acceptance (Sayles et al., 2008). The stereotype sub-scale consists of 12 items and measures perceptions about stereotyping of PLWHA (e.g., "Society looks down on people who have HIV." The disclosure concerns sub-scale consist of five items and measures concerns that others may find out the subject's HIV status (e.g., "I am concerned if I go to HIV clinic someone I know might see me"). The social relationships subscale consists of seven items that measures perceptions of what others within one's social network think about people with HIV (e.g., " people I am close to are afraid they will catch HIV from me "). The self-acceptance sub-scale consists of four items that measures the expression of guilt, shame, and feelings of insufficiency due to having HIV (e.g., "I feel ashamed to tell other people that I have HIV"). Unlike other HIV-related stigma scales, this scale was developed to capture multiple

domains of stigma including unique themes related to antiretroviral treatment use, the health care setting, and parenting. Items are rated on a 5-point Likert-type scale that ranges from “none of the time” (0) to “all of the time”(4). Mean scores for each item and subscales were transformed to 0-100 range, with lower score reflecting lower level of internalized stigma and higher score reflecting greater level of internalized stigma. As recommended by the scale’s author, the overall 28-item measure was constructed as an average for the 4 sub-scales scores rather than an average of 28 items.

This measure was psychometrically evaluated in a diverse sample of 202 PLWHA in which African American/blacks were well represented. Internal consistency reliability estimates was 0.93 for the overall measure. With the exception of the self-acceptance scale ($\alpha = 0.66$) all other sub-scales exceeded Cronbach’s alpha of 0.85. Items discriminated well across sub-scales, and correlations of the overall stigma scale with shame, social support, and mental health was supported (Sayles et al., 2008).

Brief COPE Scale

Coping strategies were measured using the Brief COPE scale. The Brief COPE (Carver, 1997) is a shortened form of the COPE (Carver, Scheier & Weintraub, 1989) that measures the degree to which an individual use different coping strategy to deal with a particular stressful event. The Brief COPE is a 28-item measure that is rated on a 4-point Likert-type scale that ranges from "I didn't do this at all" (1) to "I did this a lot" (4). This scale yields fourteen scales with 2 items each (Carver, 1997). Those scales are: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame (Carver, 1997). Mean scores for each scale were calculated with range of 2-8, with lower score reflecting

less use of coping strategy and higher score reflecting greater use of coping strategy. In this study, approach/avoidance dimension were used based on a recent meta-analysis of coping with HIV (Moskowitz et al., 2009) and other studies conducted among PLWHA. Approach coping dimension include acceptance, active coping, planning, positive reframing, using emotional support, using instrumental support, and religion. Whereas, avoidance coping dimension include self-distraction, denial, substance use, behavioral disengagement, and self-blame. Moskowitz et al. (2009) found self-blame scale factor as approach coping on meta-analysis while other recent studies conducted among PLWHA provided evidence that self-blame scale factored well in avoidance coping dimension (Mugavero et al., 2009). The Approach and avoidance coping dimensions were constructed as an average of listed scales under each dimensions. Venting and humor subscales were not classified as either dimension as they contain elements of both.

According to Carver (1997), the coefficient alpha for scales were active coping (alpha= 0.68) , planning (alpha= 0.73), positive reframing (alpha= 0.64), acceptance (alpha= 0.57), humor (alpha= 0.73), religion (alpha= 0.82), using emotional support (alpha= 0.71), using instrumental support (alpha= 0.64), self-distraction (alpha= 0.71), denial (alpha= 0.54), venting (alpha= 0.50), substance use (alpha= 0.90), behavioral disengagement (alpha= 0.65), and self-blame (alpha= 0.69). Using this instrument, Mugavero et al. (2009) formed two scales of adaptive coping styles (positive reframing, using emotional support, acceptance, religion, active) and maladaptive (denial, self-blame, and behavioral disengagement) coping styles among 474 HIV infected individuals, of which 63% were African Americans. The two scales had satisfactory internal reliability (adaptive coping = 0.74 and maladaptive coping= 0.72). A study among Malaysian women with breast cancer showed the Brief COPE scale was able to

differentiate the coping strategies between women with mastectomy and lumpectomy (Yusoff, Low & Yip, 2010).

Medical Outcomes Study Social Support Survey (MOS-SSS)

Perceived social support was measured using a 19-item Medical Outcomes Study Social Support Survey (MOS-SSS) that measure individual's perception of availability of support along four domains including tangible support (tangible), affectionate support (affection), positive social interaction (interaction), and emotional/informational support (emotion/information) (Sherbourne & Stewart, 1991). Subjects indicated how often a type of support was available if needed. The tangible support subscale consists of four items that measure the availability of material aid or behavioral assistance (e.g., "someone to help with daily chores if you were sick"). The affectionate support sub-scale consists of three items that measures the availability of expression of love and affection (e.g., "someone to love and make you feel wanted". The positive social interaction sub-scale consists three items that measures the availability of other persons to interact with you (e.g., "someone to have good time with". The emotional/informational support sub-scale consists eight items that measures the availability of other persons to understand, encourage, advice and provide guidance (e.g., "someone who you can count on to listen to you when you need to talk." Each item is rated on a 5-point Likert-type scale that ranges from "None of the time" (1) to "All of the time" (5). Mean scores for each items were transformed to 0-100 range, with lower score reflecting lower level of perceived availability of social support and higher score reflecting greater level perceived availability of social support. The total score was constructed as average of the 19 items.

Internal consistency for the MSS-SSS overall support index was very high (0.97). The validity of scale was supported by a significant correlation between the mean total score and

validity variables such as loneliness, family functioning, marital functioning, mental health, current health, physical functioning and pain intensity (Sherbourne & Stewart, 1991).

The Second Version of Short Form Health Survey (SF-12v2)

Health-Related Quality of Life (HRQoL) was measured using the second version of Short Form health survey (SF-12v2). The first version of SF-12 (SF-12v1), developed in the response to the need for shorter health survey, is a shorter version of the Medical Outcomes study 36-item Short Form Health Survey (SF-36) (Ware, Kosinski, & Keller, 1996). SF-12v1 demonstrated satisfactory psychometric properties in comparison to the SF-36 with reduction in the number of items (Ware et al., 1996). SF-12v2 includes a number of changes from SF-12v1 including item wording and response option. SF-12v2 is a 12-item self-report scale measuring an individual's behavior, perceptions and feeling regarding their health (Ware, Kosinski, Turner-Bowker, & Gandek, 2005). SF-12v2 includes one or two items from each of the eight subscales included in the original SF-36: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems and mental health (psychological distress and psychological well being). SF-12v2 scale contains two summary scores; Physical and mental health (Ware et al., 2005). The raw scores on the eight dimensions were converted to scales from 0 (lowest HRQoL) to 100 (highest HRQoL). Norm-based scoring was computed for all eight dimensions based on the norm-based scoring from the 1998 general U.S. population (Ware et al., 2005).

SF-12v2 was psychometrically evaluated among HIV-infected patients treated with ART for at least 6 months in Cameroon. The internal consistency for the measure was 0.88, reflecting satisfactory internal score consistency. Factor analysis suggested a two-factorial solution in which the factor loadings of most items were highest on the component theoretically assumed for

summary scales. Subjects with higher HRQoL had better clinical status and reported higher ART adherence (Boyer et al., 2011). The internal consistency reliability method, that examines the equivalence of responses within the same test from a single administration, is not applicable for SF 12v2 scale. According to Ware et al.(2002), SF12v2 items are relatively heterogeneous compared with most health status scales and these items were selected because of the unique reliable variance in estimating the physical and mental health it contained. Furthermore, the internal consistency reliability cannot be tested for the single-item measures of SF12v2. Thus, Ware et al (2002) concluded that internal consistency reliability method underestimate the reliability of SF12v2 summary measures and they recommend to use alternative forms estimation methods that is beyond the scope of the study.

Table 1 Study Instruments Internal Consistency Reliabilities (n=100)

| Instruments | Alpha | # items |
|--|-------|---------|
| Multi-dimensional Measure of Internalized HIV Stigma | | |
| Stereotypes subscale, | .87 | 12 |
| Disclosure concerns subscale, | .94 | 5 |
| Social relationships subscale | .89 | 7 |
| Self-acceptance subscale | .80 | 4 |
| Overall HIV-related stigma | .85 | 4 |
| Brief Coping | | |
| Approach | .81 | 14 |
| Avoidance | .75 | 10 |
| Medical Outcomes Study Social Support Survey | | |
| Tangible support | .96 | 4 |
| Affectionate support | .96 | 3 |
| Positive social interaction | .96 | 3 |
| Emotional/informational support | .95 | 8 |
| Overall Social support Index | .97 | 19 |

Data Management and Analysis

The overall goal is to gain an understanding of the relationship between perceived HIV-related stigma, coping strategies, perceived social support and health related quality of life among black PLWHA, and differences between foreign-born and native groups. The following variables were measured to accomplish the goal of the study: perceived HIV-related stigma, coping strategies, perceived social support and health related quality of life. The selection of variables was based on a review of HIV literature, primary investigator's professional experience and the transactional model of stress and coping.

Data collection was guided by the IRB approved study protocol. Participants were interviewed using a structured questionnaire. The principal investigator monitored data accuracy and completion of questionnaires before participants left the clinic. Data entry was performed at the Nell Hodgson Woodruff School of Nursing (NHWSO) on a password protected network. The hard copies of the inventories were stored in a locked file cabinet at NHWSO.

SPSS 20.0 software package was used for data analysis. Preliminary data editing steps included examining all variables for accuracy of data entry, missing values and satisfaction of test assumptions. There were very minimal missing data. One item missing from the HIV-related stigma scale was replaced by the mean for all cases. All instruments were scored according to their guide. The internal consistency reliability of study instruments was computed except for the SF12v2 scale for the reason explained under the instrument description. Variables were screened for normality through examination of skewness and kurtosis tests and normal curves on histogram. All tests for statistical significance were conducted at 95 percent confidence level ($\alpha = 0.05$), unless otherwise stated.

Descriptive statistics such as frequencies for categorical variables and means, standard deviations, and range for continuous variables were conducted to describe the study participants and major variables of interest. Furthermore, Pearson correlations, chi square test and independent t-test were conducted to describe difference between native-born and foreign-born PLWHA groups. For inferential statistics, bivariate and multivariate analyses were performed. Statistical procedures that were used to achieve the specific research questions are described below.

Research Question 1: To examine the differences between native-born and foreign-born black PLWHA on HIV-related stigma, coping strategies, social support and HRQoL, the following null hypothesis were tested.

Null Hypothesis 1-A: There will be no significant difference between the mean total score of the perceived HIV-related stigma among native-born black PLWHA and the mean total score of perceived HIV-related stigma among foreign-born black PLWHA.

Null Hypothesis 1-B: There will be no significant difference between the mean score of coping strategies (approach and avoidance) among native-born black PLWHA and the mean score of coping strategies (approach and avoidance)among foreign-born black PLWHA.

Null Hypothesis 1-C: There will be no significant difference between the mean total score of perceived social support availability among native-born black PLWHA and the mean total score of perceived social support availability among foreign-born black PLWHA.

Null Hypothesis 1-D: There will be no significant difference between the mean summary scores (physical and mental) of HRQoL among native-born black PLWHA and the mean summary scores (physical and mental) of HRQoL among foreign-born black PLWHA.

Statistical Procedure: Independent-samples t-tests are used to compare the mean scores for the two groups on all variables of interest.

Research Question 2: To understand the mediation effect of avoidance coping in the relationship between perceived level of HIV-related stigma and mental summary score of HRQoL, the following null hypothesis were tested. The basic mediation model synthesized in this study is shown in Figure 2.

Null Hypothesis 2-A: There will be no significant association between perceived level of HIV-related stigma and mental summary score of HRQoL.

Null Hypothesis 2-B: Avoidance coping strategy does not mediate the relationship between perceived level of HIV-related stigma and mental Summary score of HRQoL. There will be no significant indirect effect (the change in the level of perceived HIV-related stigma would be related to the use of avoidance coping strategies, which, in turn would be related to the mental summary score of HRQoL). The bias-corrected bootstrap confidence interval for the indirect effect will include zero with 95% confidence.

Statistical Procedure: To test the mediation effect of avoidance coping, Preacher and Hayes (2004) method was used to estimate the indirect effect with a bootstrap approach to obtain confidence intervals, as well as a regression coefficient to estimate bivariate relationships. The indirect effect of HIV-related stigma on mental summary score of HRQoL through avoidance coping measured as the product of the path from HIV-related stigma to avoidance coping (a) and the path from avoidance coping to mental summary score of HRQoL(b) and referred herein after as *ab*. Preacher and Hayes (2004) method provided a bootstrap estimate of the indirect effect *ab*, an estimated standard error, and both 95% and 99% confidence intervals for population value of *ab*. The bootstrapping was accomplished by taking 1000 samples of size 100 (100 is the original

sample size) from the data using sampling with replacement, and computed the indirect effect, ab , in each sample. The point estimate of ab was simply the mean ab computed over the 1,000 samples, and the estimated standard error was the standard deviation of the 1,000 ab estimates. To derive the 95% confidence interval, the elements of the vector of 1,000 estimates of ab were sorted from low to high. The lower limit of the confidence interval was defined as the 25th score of the sorted distribution 1,000 estimates, and the upper limit was defined as the 976th score in the distribution. If the 95% confidence interval excluded 0, the quantity being tested is declared statistically significant.

Thus, the indirect effect (hypothesis 2-B) was considered significant if bias-corrected bootstrap 95% confidence interval exclude zero. Bootstrapping method circumvent the power problem introduced by asymmetries and other forms of non-normality in the sampling distribution of the indirect effect of HIV-related stigma on mental summary score of HRQoL through avoidance coping (Preacher & Hayes , 2004). It is not based on large-sample theory and can be applied to small samples with more confidence. Bootstrapping is considered a non-parametric approach to effect-size estimation and hypothesis testing that makes no assumptions about the shape of the distributions of the variables or the sampling distribution of the statistic (Preacher and Hayes, 2004). It is therefore appropriate for this small sample. The direct effect (hypothesis 2-A) is considered significant if the p value for regression b (YX) was less than .05. The regression coefficient b (YX) is the effect of HIV-related stigma (X) on the mental summary scores of HRQoL (Y) in the absence of avoidance coping (M).

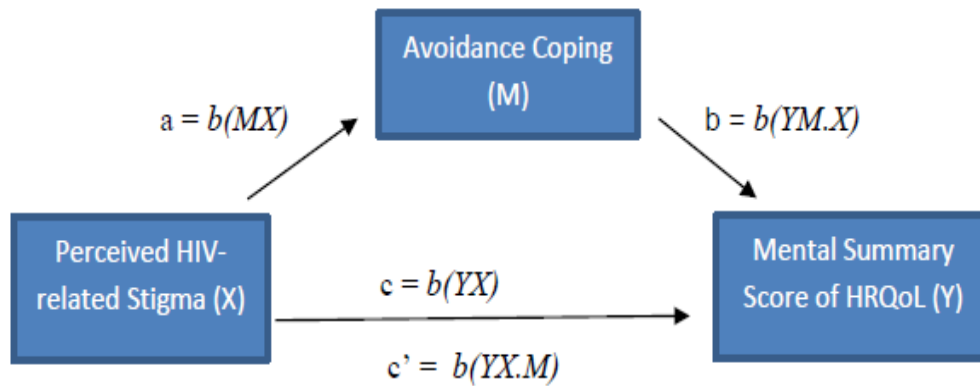


Figure 2 Mediation Model of the Study.

Research Question 3 and 4: To understand the moderation effect of nativity and perceived social support on the mediation effect of avoidance coping in the relationship between the level of perceived HIV-related stigma and mental summary score of HRQoL, the following null hypotheses were tested. The moderated mediation models synthesized in this study are shown in Figure 3 and Figure 4.

Null Hypothesis 3-A: The relationship of perceived HIV-related stigma and mental summary score of HRQoL will not be moderated by nativity. There will be no difference in the relationships between native-born and foreign-born black PLWHA.

Null Hypothesis 3-B: Nativity does not moderate the indirect effect (the path between perceived HIV-related stigma and avoidance coping, and the path between avoidance coping and mental summary score of HRQoL). There will be no difference between the mediation result for native-born and foreign-born black PLWHA.

Null Hypothesis 4-A: The relationship of perceived HIV-related stigma and mental summary score of HRQoL will not be moderated by level of perceived social support. There will be no

difference between the mediation result between the groups that perceived low and high level of availability of social support.

Null Hypothesis 4-B: Perceived social support does not moderate the indirect effect (the path between perceived HIV-related stigma and avoidance coping, and the path between avoidance coping and mental summary score of HRQoL). There will be no significant difference between the mediation result for the groups that perceived low and high level of availability of social support.

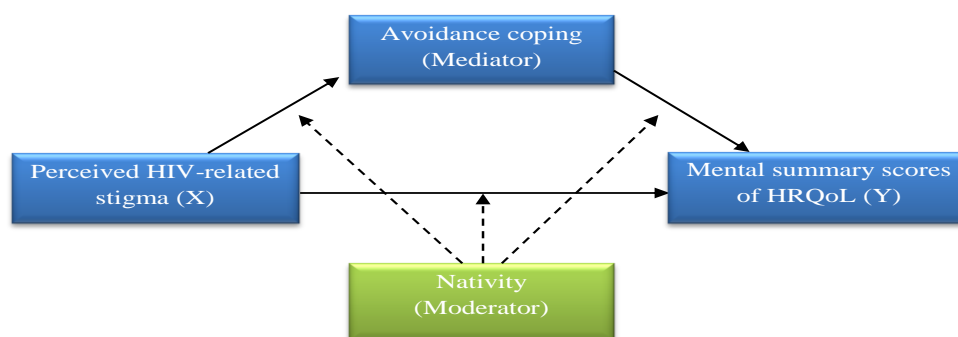


Figure 3 Moderated Mediated Model for Nativity.

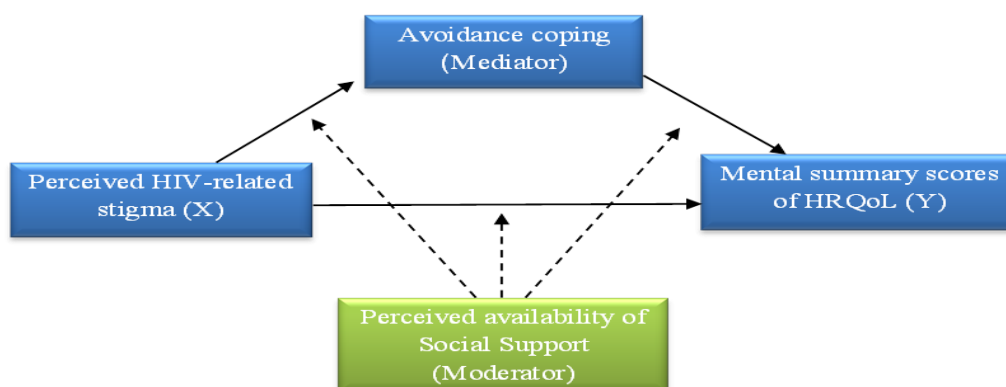


Figure 4 Moderated Mediated Model for perceived Social Support.

Statistical Procedure: To test the moderation of the relationship between perceived HIV-related stigma and mental summary score of HRQoL by nativity and social support (Hypothesis 3-A & 4-A), the difference in the regression coefficient $b(YX)$ was assessed (see Figure 2). The regression coefficient $b(YX)$ is the effect of HIV-related stigma (X) on the mental summary scores of HRQoL (Y). If the significance of the regression coefficient $b(YX)$ for the two levels of moderator variables are different, such that $b(YX)$ is significant for one moderator level while it is not for the other, it is considered moderated by the moderator variable. If the significance level or p values of the regression coefficients $b(YX)$ are similar, either both are significant or both are not significant, it is considered not moderated by the moderator variable.

To test the moderated mediation model, subgroup approach was used to combine moderation and mediation tests. This approach involved splitting the sample into subgroups that represent two different levels of moderator variables. Since nativity is already a two level categorical variable, only the total score of perceived level of social support was dichotomized into 'high' and 'low' categories. The median split method was used. First, native-born and foreign-born groups were dichotomized separately using the median value within the group to prevent over-representation of the group with higher mean in the high social support group and vice versa since the two groups significantly differ in their mean total score of perceived social support. Then, the two low social support categories (low social support within native-born participants and low social support within foreign-born participants) were combined to create the low social support groups. Likewise, the two high social support categories (high social support within native-born participants and high social support within foreign-born participants) were combined to create the high social support groups.

Then mediation tests were assessed using Preachers and Hayes (2004) bootstrapping method for both the low and high social support groups. If evidence for mediation differs between the low and high social support groups in case of hypothesis 3-B, it was concluded that mediation was moderated by nativity. Similarly, if evidence for mediation differs between the low and high social support group after stratified by nativity in case of hypothesis 4-B, it was concluded that mediation was moderated by the level of perceived social support. Even though this approach does not quantify and test the differences in mediation between the two levels of moderator variables, it does not suffer from the limitation of the traditional methods of mediation tests as it uses bootstrapping method to test the mediation effect. The subgroup approach has been recommended to test moderation in context of mediation (Wegner & Fabrigar, 2000) and structural equation modeling (Rigdon, Schumacker, & Wothke, 1998).

Protection of Human Subjects

This study was governed by the Institutional Review Boards (IRB) of Emory University and the Georgia Department of Public Health. IRB categorized the study under low risk to subjects. Standardized protocol was established to minimize risks, including risks to confidentiality. All data were handled confidentially and used solely for the purpose of this research. The interview took approximately 30 minutes to complete. Prior to consent, participants were informed of the complete time commitment, benefits and the fact that their participation is voluntary; withdrawal allowed at any time with no effect on the services and care provided at the RWECC. Informed consent was signed before initiation of the interview. Potential risks to subjects in this study were minimal and include the inconvenience of time that was used to complete the interview. There were no known adverse events.

To reduce the risks to confidentiality, the following strategies were employed: 1) data were coded using individual identification codes, 2) names and identification codes stored separately, 3) informed consent forms kept separate from the data; 4) all data kept in locked file cabinets at Emory University NHWSON; and 5) only the researchers have access to the raw data. All computer databases were password protected. All electronic and paper data maintained according to Emory University regulations. Publications from this study will not name or describe in an identifiable way any individual participant.

There were no direct benefits for the participants of this study other than feeling a sense of accomplishment for helping to expand the scientific knowledge in the area of HIV-related stigma. This study provided valuable information about HIV-related stigma and health-related quality of life among foreign-born and Native black PLWHA. Information gained from this investigation contributes to the development of intervention approaches to cope with HIV-related stigma and improve quality of life in this group. The benefits of the proposed study outweigh the very slight possibility of negative consequences.

Inclusion of Women, Minority and Children

At the end of October 2011, there were 736 actively enrolled patients, of whom 69% were male, 29% were female and 1.6 % were transgender at the RWECC. Participant for this study were all black or Black including black Hispanic. One of the inclusion criteria for the study was being 18 years of age and older. Children age 18 –21 were included. The questionnaire developed in this study was designed for adults who are developmentally capable of insight into self-behaviors. Age 18 was also necessary for independent consent. We targeted women enrollment to achieve a 30% or higher representation of black female PLWHA based on the

clinic racial and gender composition described earlier. Since there was no data regarding the percentage of foreign-born patient enrolled in the clinic, foreign-born patients representation was determined based on the statistical requirements to run tests of mean difference. Thus, it was determined that at least 30 foreign-born participants were needed for this study. A weekly assessment of recruitment progress was conducted. At the closing of the data collection, a total of 100 black or Black PLWHA enrolled in the study and all targeted enrollment goals were met.

CHAPTER FOUR: RESULTS AND FINDINGS

This chapter presents the results of the analysis addressing the research questions and hypotheses set forth in previous chapters. This study examines the relationships between perceived HIV-related stigma, coping strategies, and health-related quality of life (HRQoL) among people living with HIV/AIDS (PLWHA). In addition, the study explores the moderation effects of nativity (native-born versus foreign-born) and perceived availability of social support (low versus high) in the relationship between perceived HIV-related stigma, avoidant coping strategy, and mental summary scores of HRQoL. The results are divided into five major parts. First, sample characteristics are described. Second, a preliminary analysis of the overall data is presented. The preliminary analysis includes the result of Pearson product-moment correlations (hereinafter referred to simply as Pearson correlations) calculated to examine the relationships between dependent and independent variables. Third, the results of independent sample *t*-tests are presented to address the first research question. Fourth, the results of the Preacher and Hayes mediation test for research question two are presented. Fifth, the results of the two moderation mediation test conducted to test the third and fourth research questions are described. All statistical analyses were performed using the Statistical Package for Social Science (SPSS) version 20. All tests for statistical significance were conducted at the 95 percent confidence level ($\alpha = 0.05$), unless otherwise stated.

Sample Characteristics

A total of 100 black PLWHA participated in this study. The mean age for the sample was 42 (*SD* 10.4, Range 21-67) years. Sixty three of the participants were born in the United States. Of the 37 foreign-born participants, almost half of them, 18 (48.6%), were born in Ethiopia, followed by 17 participants from several other sub-Saharan African countries (Ivory Coast, Cameroon, Liberia, Sudan, Kenya, Rwanda, and Zambia) and two were from the Caribbean. The mean number of years lived in the U.S. for foreign-born participants was 7.65 (*SD* 5.41, Range 1-20) years. Among all participants, the majority (74%) identify themselves as heterosexual. More than half live with family (59%), were unemployed (57%), and reported an annual income of less than \$10,999 (66%). The majority of the participants were Christian (87%) and on ART medication (81%).

Categorical demographic variables were dichotomized and compared by nativity. Those variables are sexual identity (heterosexual versus homosexual/bisexual), income (less than or equal to \$10,999 versus more), being on ART (yes or no), living arrangement (living alone versus with others), educational status (high school versus above high school), disclosure of HIV status (yes or no), marital status (in a relationship versus no current relationship), and employment (employed versus unemployed). Chi square tests for categorical variables were employed to examine the difference between native and foreign-born groups. Categorical demographic characteristics of the sample by nativity are shown in Table 2.

Table 2 Categorical Demographic Variables by Native-born (N=63) and Foreign-born (N=37) Groups

| <i>Categorical Variable</i> | <i>Full Sample n(%)</i> | <i>Native-born n(%)</i> | <i>Foreign-born n(%)</i> | $\chi^2(1)$ | <i>P</i> |
|-----------------------------|-----------------------------|-----------------------------|------------------------------|-------------|-------------|
| Gender | | | | | |
| Male | 45 | 26 (56.7) | 26 (29.7) | 6.68 | .023 |
| Female | 52 | 34 (43.3) | 11 (70.3) | | |
| Sexual Identity | | | | | |
| Heterosexual | 74 | 38 (60.3) | 36 (97.3) | 16.57 | .000 |
| Homosexual/Bisexual | 26 | 25 (39.7) | 1 (2.7) | | |
| Educational level | | | | | |
| ≤ High school/GED | 55 | 35 (55.6) | 20 (54.1) | .02 | 1 |
| College and higher | 45 | 28 (44.4) | 17 (55.9) | | |
| Marital Status | | | | | |
| In relationship | 26 | 10(15.9) | 16 (43.2) | 9.08 | .004 |
| No relationship | 74 | 53(84.1) | 21 (56.8) | | |
| Living arrangement | | | | | |
| Living alone | 21 | 18 (28.6) | 3 (8.1) | 5.88 | .021 |
| Living with others | 79 | 45 (71.4) | 34 (91.9) | | |
| Employment Status | | | | | |
| Employed | 43 | 26 (41.3) | 17 (45.9) | .21 | .68 |
| Unemployed | 57 | 37 (58.7) | 20 (54.1) | | |
| Average annual income | | | | | |
| \$0-10,999 | 66 | 42 (66.7) | 24 (64.9) | .03 | 1 |
| \$11,000 and above | 34 | 21 (33.3) | 13 (35.1) | | |
| Religion | | | | | |
| Christian | 87 | 55 (94.8) | 32 (86.5) | 2.04 | .255 |
| Muslim | 8 | 3 (5.2) | 5 (13.5) | | |
| Having children | | | | | |
| No child | 37 | 26 (41.3) | 11 (29.7) | 1.33 | .288 |
| At least one child | 63 | 37 (58.7) | 26 (70.3) | | |

| <i>Categorical Variable</i> | <i>Full Sample n(%)</i> | <i>Native-born n(%)</i> | <i>Foreign-born n(%)</i> | $\chi^2(1)$ | <i>P</i> |
|-----------------------------|-----------------------------|-----------------------------|------------------------------|-------------|-------------|
| AIDS diagnosis | | | | | |
| No | 83 | 58 (92.1) | 25 (67.6) | 9.91 | .002 |
| Yes | 17 | 5 (7.9) | 12 (32.4) | | |
| Currently on ART medication | | | | | |
| No | 19 | 13 (20.6) | 6 (16.2) | .3 | .613 |
| Yes | 81 | 50 (79.4) | 31 (83.8) | | |
| Knowing recent CD4 count | | | | | |
| No | 37 | 21 (33.3) | 16 (43.2) | .98 | .392 |
| Yes | 63 | 42 (66.7) | 21 (56.8) | | |
| Smoking | | | | | |
| No | 58 | 26 (41.3) | 32 (86.5) | 19.56 | .000 |
| Yes | 42 | 37 (58.7) | 5 (13.5) | | |
| Drinking alcohol | | | | | |
| No | 66 | 34 (54.0) | 32 (86.5) | 10.98 | .001 |
| Yes | 34 | 29 (46.0) | 5 (13.5) | | |
| Disclose HIV status | | | | | |
| No | 12 | 1 (1.6) | 11 (29.7) | 17.48 | .000 |
| Yes | 88 | 62 (98.4) | 26 (70.3) | | |

Table 3 Continuous Demographic Variables by Native-born and Foreign-born Groups

| <i>Continuous Variable</i> | <i>Full Sample (N=100) M(SD)</i> | <i>Native-born (N=63) M(SD)</i> | <i>Foreign-born (N=37) M(SD)</i> | <i>t</i> | <i>P</i> |
|---------------------------------------|--|---|--|----------|------------|
| Age | 42 (10.4) | 42.03 (10.2) | 42.03 (11.17) | .002 | .99 |
| Number of years since HIV + | 10.64 (6.55) | 11.78 (7.28) | 8.7 (4.58) | 2.6 | .01 |
| Age at first HIV+ | 32.39 (9.3) | 31.25 (8.5) | 34.32 (10.37) | -1.61 | .11 |
| Number of years on ART (n=81) | 9.36 (5.74) | 10.28 (6.17) | 7.87 (4.7) | 1.86 | .07 |
| Self-reported CD4 count (n=63) | 571 (226) | 588 (217) | 538 (245) | .83 | .41 |

Independent T-test analyses for continuous variables are employed to examine the difference between native and foreign-born groups. Demographic characteristics of the sample that are continuous variables are shown in Table 3. The only continuous variable that was significantly different between the native-born and foreign-born patients was the number of years since HIV diagnosis. Overall, there were no statistical differences with regard to age, education, employment, income, religion, number of children, being on ART, number of years on ART, knowing the recent CD4 count, self-reported CD4 count, and number of years elapsed between initial HIV positive test and diagnosis of AIDS. However, there were significant differences in gender, sexual identity, marital status, living arrangement, and number of years since tested positive for HIV, diagnosis with AIDs, smoking status (yes or no), drinking alcohol status (yes or no), and voluntary disclosure to at least one person. Compared to native participants, foreign-born participants were more likely to be female, identify self as heterosexual, report being in a relationship, live with someone, and to report being diagnosed with AIDs. Foreign-born participants were also less likely to report smoking, drinking alcohol, volunteer disclosure of HIV status to at least one person, and less number of years since tested HIV positive compared with native participants.

Preliminary Analysis

Prior to conducting hypotheses tests, demographic characteristics (e.g., age, gender, race, etc.) and major variables of interest (perceived HIV-related stigma, coping strategies, perceived social support, and health-related quality of life) were assessed for assumptions of multivariate analysis. The assumption of normality was met by verifying that there was no significant skewness or kurtosis, and by producing and inspecting histograms and normal probability plots. Linearity and homoscedasticity were verified by producing and inspecting bivariate scatter plots.

In addition, inspection of the correlation matrix revealed no bivariate correlations above 0.70 among the variables of interest, indicating that multicollinearity did not exist.

Correlation between Demographic Variables

Participants who completed high school reported significantly higher income ($r = .284, p = .004$), however no significant correlation was found between education and employment status ($r = -.189, p = .06$). Participants who were older ($r = .438, p = .000$), female ($r = .348, p = .000$), and heterosexual ($r = -.348, p = .000$) reported having at least one child which were significant. Having a child did not significantly correlate with marital status ($r = -.124, p = .22$). Participants who self-identified as homosexual/bisexual were more likely to report smoking ($r = .284, p = .005$) and drinking alcohol ($r = .345, p = .000$). Male participants were more likely to report smoking ($r = -.330, p = .001$) but no significant correlation was identified between gender and drinking status ($r = -.157, p = .12$).

Neither recalling recent CD4 counts nor self-reported CD4 count correlated with any of the demographic and major variables of interest, except participants who answered yes to drinking alcohol reported higher CD4 counts ($r = .227, p = .028$). Voluntary disclosure of HIV status to at least one person correlated significantly with sexual identity ($r = .219, p = .029$) and drinking status ($r = .2, p = .05$). Those who identify as heterosexual and reported no drinking of alcohol were less likely to disclose their HIV status.

Correlations between Demographic Variables and Major Variables

The correlation matrix indicated significant correlations between some demographic variables and major variables of interest. As presented in Table 4, perceived HIV-related stigma scores were shown to have a significant positive correlation with nativity, gender, being on ART medication and avoidance coping. Those who were foreign-born, female, and on ART medication perceived a significantly higher level of HIV-related stigma. As level of perceived

HIV-related stigma increased, the use of avoidance coping strategies increased. Perceived level of HIV-related stigma scores were also shown to have a significant negative correlation with sexual identity, smoking, drinking, disclosure to at least one person, approach coping, perceived social support, and mental summary scores of HRQoL. Participants identified as heterosexuals, non-smokers, and those who reported no alcohol consumption perceived a significantly higher level of HIV-related stigma. As level of perceived HIV-related stigma increased, the level of approach coping, perceived social support, tendency to disclose, and mental summary scores of HRQoL decreased. Among foreign-born participants, the length of stay in the U.S. significantly negatively correlate with perceived level of HIV-related stigma ($r = -.415, p = .01$).

The physical summary scores of HRQoL correlated with age, having a child, drinking alcohol status, and number of years on ART. Participants who are older, have at least one child ($r = -.263, p = .02$), and have been on ART longer ($r = -.236, p = .034$) had significantly lower physical summary scores of HRQoL, while those who answered yes to drinking alcohol had significantly higher physical summary scores of HRQoL ($r = .243, p = .015$). As shown in table 4, physical summary scores of HRQoL correlated with none of the major psychosocial variables such as HIV-related stigma, approach and avoidance coping strategies, social support and mental summary score of HRQoL.

The mental summary scores of HRQoL were significantly negatively correlated with nativity, perceived HIV-related stigma, and use of avoidance coping. As the level of perceived HIV-related stigma and use of avoidance coping strategies increased, the mental summary scores of HRQoL decreased. Foreign-born participants had significantly lower mental summary scores of HRQoL. Mental summary scores showed significant positive correlation with disclosure to at least one person and perceived level of social support. As the level of perceived social support

increased, the mental summary scores of HRQoL increased as well. Participants who disclosed their HIV status to at least one person had higher mental scores of HRQoL. Mental summary scores of HRQoL positively correlated with having at least one child ($r = .197, p = .049$) and the number of years being HIV positive ($r = .2, p = .05$). It did not show significant correlation with number of years on ART ($r = .2, p = .074$).

Independent T-test

Descriptive statistics for the perceived HIV-related stigma scale and its subscales, the Brief COPE avoidance and approach coping strategies, the perceived social support and its subscales, and the mental and physical summaries of SF 12v2 scale are listed in Table 5. Independent *t*-test analyses were computed to address research question one. There were no significant differences in coping strategies (approach and avoidance) and physical summary scores of HRQoL between foreign-born and native born blacks. Foreign-born black PLWHA had lower mental summary scores of HRQoL compared to native black PLWHA. With the exception of the tangible support subscale, foreign-born persons had significantly lower scores on all social support subscales and significantly higher scores on all stigma subscales than native black PLWHA.

Table 4 Correlation Matrices of Selected Variables (n=100)

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 |
|-------------------------------------|----------------|----------------|----------------|----------------|---------------|---------------|---------------|----------------|----------------|----------------|--------------|----------------|---------------|-------|----|
| 1. Age | 1 | | | | | | | | | | | | | | |
| 2. Nativity | .000 | 1 | | | | | | | | | | | | | |
| 3. Gender | .146 | .235* | 1 | | | | | | | | | | | | |
| 4. Sexual identity | -.147 | -.407** | -.564** | 1 | | | | | | | | | | | |
| 5. Being on ART | .156 | .054 | .126 | -.062 | 1 | | | | | | | | | | |
| 6. Smoking status | -.169 | -.442** | -.330** | .281** | -.104 | 1 | | | | | | | | | |
| 7. Drinking status | -.126 | -.331** | -.157 | .345** | -.083 | .245* | 1 | | | | | | | | |
| 8. Disclosure | -.118 | -.418** | -.025 | .219* | -.022 | .190 | .200* | 1 | | | | | | | |
| 9. Number of yrs since HIV + | .475** | -.227* | -.115 | .134 | .157 | .053 | -.093 | .220* | 1 | | | | | | |
| 10. HIV-related stigma | .048 | .613** | .217* | -.296** | .318** | -.256* | -.204* | -.436** | -.162 | 1 | | | | | |
| 11. Approach coping | .043 | -.008 | .032 | .035 | .045 | -.057 | .140 | .130 | .030 | -.197* | 1 | | | | |
| 12. Avoidance coping | -.257** | .054 | -.047 | .050 | .061 | .278** | .143 | -.145 | -.281** | .442** | -.076 | 1 | | | |
| 13. Perceived social support | .056 | -.413** | .018 | .183 | -.030 | .028 | .078 | .442** | .091 | -.522** | .213* | -.365** | 1 | | |
| 14. Physical summary SF12v2 | -.419** | .017 | -.006 | .115 | -.039 | -.040 | .243* | .163 | -.138 | -.004 | -.169 | .042 | .034 | 1 | |
| 15. Mental summary SF12v2 | .160 | -.328** | -.109 | .045 | -.117 | -.092 | .003 | .280** | .197* | -.623** | .037 | -.450** | .508** | -.099 | 1 |

Table 5 Mean and Standard Deviation of Psychosocial Variables by Native-born and Foreign-born Groups

| Variable | Total sample (N=100) | | Native-born (N=63) | | Foreign-born (N=37) | | T-Test | |
|--|----------------------|-----------|--------------------|-----------|---------------------|-----------|----------|----------|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | <i>t</i> | <i>P</i> |
| HIV-related stigma^a | | | | | | | | |
| • Stereotypes | 56.61 | 21.90 | 49.58 | 21.53 | 68.58 | 16.95 | -4.59 | .000 |
| • Disclosure concerns | 51.60 | 39.48 | 34.76 | 32.21 | 80.27 | 34.03 | -6.68 | .000 |
| • Social relationship | 33.63 | 32.95 | 18.25 | 19.74 | 59.79 | 36.60 | -6.69 | .000 |
| • Self-acceptance | 73.00 | 28.58 | 63.49 | 28.60 | 89.19 | 20.23 | -5.24 | .000 |
| • Overall HIV stigma | 53.71 | 26.08 | 41.52 | 19.16 | 74.46 | 23.14 | -7.67 | .000 |
| Approach coping | 5.93 | 1.08 | 5.93 | 1.15 | 5.91 | .94 | .08 | .94 |
| Avoidance coping | 3.61 | 1.11 | 3.56 | 1.16 | 3.69 | 1.03 | -.53 | .6 |
| Perceived social Support | | | | | | | | |
| • Tangible | 74.00 | 31.52 | 77.78 | 30.43 | 67.57 | 32.70 | 1.58 | .118 |
| • Affection | 77.00 | 29.54 | 83.73 | 27.00 | 65.54 | 30.50 | 3.09 | .003 |
| • Interaction | 74.00 | 28.65 | 81.08 | 27.16 | 61.94 | 27.39 | 3.39 | .001 |
| • Emotion/Information | 66.06 | 31.31 | 78.17 | 25.99 | 45.44 | 28.92 | 5.83 | .001 |
| • Overall social support | 67.07 | 25.64 | 75.15 | 22.65 | 53.30 | 24.81 | 4.49 | .000 |
| Physical Health summary scores of SFv2 12^b | 52.07 | 9.84 | 51.95 | 8.39 | 52.29 | 12.04 | -.16 | .87 |
| Mental Health summary scores of SFv2 12^b | 46.48 | 12.96 | 49.72 | 11.32 | 40.96 | 13.82 | 3.44 | .001 |

NOTE: M = Mean ; SD = Standard Deviation; a = Higher score indicates higher level of internalized stigma; b = Higher scores indicates higher quality of life

Mediation Test of Avoidance Coping

Preacher and Hayes' (2004) SPSS syntax command **SOBEL** was used to estimate a bootstrap re-samples of 1000 indirect effect and obtain confidence intervals, as well as the regression coefficient for each paths.

The null hypotheses tested and respective findings for the research question 2 were:

Null Hypothesis 2-A: There will be no significant relationship between perceived level of HIV-related stigma and mental summary scores of HRQoL.

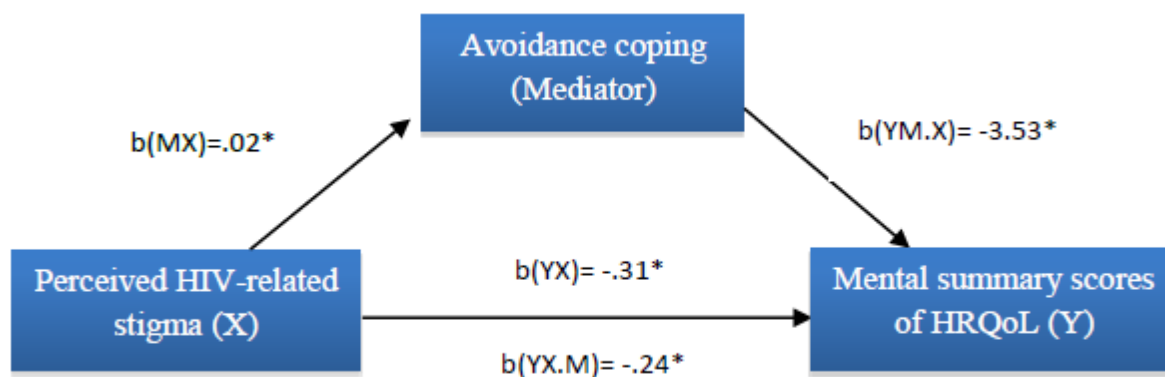


Figure 5 Regression Coefficients for Total, Direct and Indirect Paths. * $P < .05$

Findings: As depicted in Figure 5, the regression for the relationship between perceived level of HIV-related stigma (X) and the use of avoidance coping (M), $b(MX)$, was positive (.02) and significant ($p = .000$). As the level of perceived HIV-related stigma increases, the use of avoidance coping strategy increases. The regression for the relationship between the use of avoidance coping (M) and mental summary scores of HRQoL (Y) controlled for perceived level of HIV-related stigma (X), $b(YM.X)$, was negative (-3.53) and significant ($p = .000$). As the use of avoidance coping increases, the level of mental summary score of HRQoL decreases regardless of the level of perceived HIV-related stigma. The regression for the direct relationship

between perceived level of HIV-related stigma (X) and mental summary scores of HRQoL (Y), b (YX), was negative (-.31) and significant ($p = .000$). The regression for the relationship between perceived level of HIV-related stigma (X) and mental summary scores of HRQoL (Y) controlled for avoidance coping (M) (b (YX.M)) was also negative (-.24), and significant ($p = .000$). As the level of perceived HIV-related stigma increases, the level of mental summary score of HRQoL decreases in both cases when the use of avoidance coping was controlled and was not controlled. However, the negative relationship between perceived HIV-related stigma and mental summary score of HRQoL (b (YX) = - 0.31) becomes smaller after controlling for avoidance coping (b (YX.M) = - 0.24). The next hypothesis tests whether this change is different from zero with 95% confidence using bootstrapped sample.

Null Hypothesis 2-B: Avoidance coping strategy does not mediate the relationship between perceived level of HIV-related stigma and mental summary score of HRQoL, such that the bias-corrected bootstrap confidence interval for the indirect effect will include zero with 95% confidence. The bootstrap output for indirect effect is shown in Table 6 and bootstrapped sampling distribution depicted in Figure 6.

Table 6 Bootstrap Result for Mediation Test

| BOOTSTRAP RESULTS FOR INDIRECT EFFECT | | | | | | |
|---------------------------------------|--------|-------|---------------|---------------|----------|----------|
| | Mean | s.e. | LL 95 CI | UL 95 CI | LL 99 CI | UL 99 CI |
| Effect | -.0657 | .0205 | -.1091 | -.0292 | -.1305 | -.0145 |
| SAMPLE SIZE | 100 | | | | | |
| NUMBER OF BOOTSTRAP RESAMPLES | 1000 | | | | | |

Findings: The bias-corrected bootstrap 95% confidence interval estimated that the true indirect effect lies between -0.1091 and -0.0292 with 95% confidence. Because zero is not in the 95% confidence interval, the indirect effect is considered different from zero. Thus, avoidance coping serve as a mediator between perceived HIV-related stigma and mental summary scores of HRQoL.

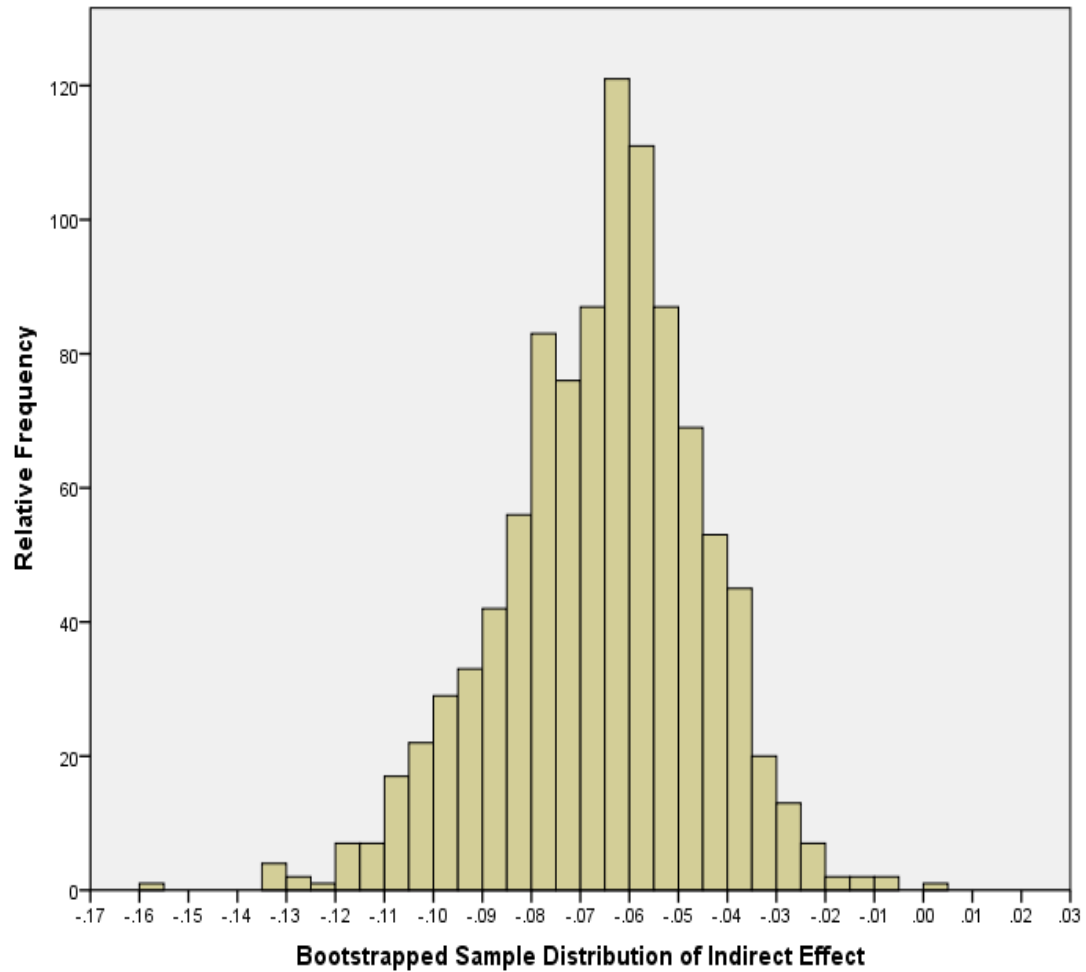


Figure 6 A Graphic Depiction of the Bootstrapped Sampling Distribution of the Indirect Effect.

Moderated Mediation Tests

Nativity as a Moderator

The subgroup approach was used to combine moderation and mediation analyses to examine whether nativity moderated the total effect of perceived HIV-related stigma on mental summary score of HRQoL as well as the mediation effect of avoidance coping between the two variables. The groups of native-born and foreign-born represent different levels of the moderator variable. Preacher and Hayes' (2004) SOBEL outputs were used to estimate the regression coefficient between the perceived HIV-related stigma on mental summary score of HRQoL and the bootstrapped indirect effect through the mediator avoidance coping for native-born and foreign-born groups.

The null hypotheses tested and respective findings for the research question 3 were:

Null Hypothesis 3-A: The relationship of perceived HIV-related stigma and mental summary score of HRQoL will not be moderated by nativity. There will be no difference in this relationship between the native and foreign-born black PLWHA groups.

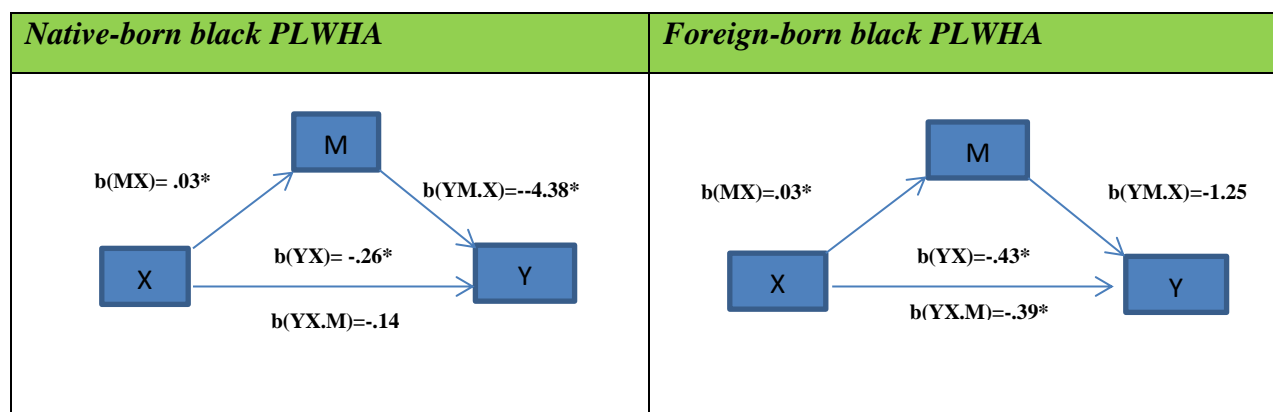


Figure 7 Regression Coefficients for Direct and Indirect Paths by Nativity. X is perceived HIV-related stigma, M is avoidance coping and Y is mental summary scores of HRQoL. *P < .05

Findings: The regression coefficients for direct and indirect paths are depicted in Figure 7. The relationship between perceived HIV-related stigma and mental summary scores of HRQoL is significant for both the native-born and foreign-born groups. The regression coefficient for foreign-born group is notably higher (-.43) compared to the native-born group (-.26). The relationships between perceived level of HIV-related stigma and mental summary scores of HRQoL are inverse for both groups. As the level of perceived HIV-related stigma increases, the mental summary scores of HRQoL decreases. Additional findings are 1) when perceived HIV-related stigma (X) is controlled, there is a significant negative association between the use of avoidance coping (M) and mental summary scores of HRQoL(Y) for the native group but not for the foreign-born group ($b(YM.X)$), 2) when the use of avoidance coping (M) is controlled, there is a significant negative association between perceived HIV-related stigma (X) and mental summary scores of HRQoL(Y) for the foreign-born group but not for the native-born group ($b(YX.M)$).

Null Hypothesis 3-B: Nativity does not moderate the indirect effect (the path between perceived HIV-related stigma and avoidance coping, and the path between avoidance coping and mental summary score of HRQoL). There will be no difference between the mediation results for native and foreign-born black PLWHA groups.

Findings: The bootstrap output for indirect effects for both groups are depicted in Table 7. The bias-corrected bootstrap 95% confidence interval estimated that the true indirect effect lies between -0.2140 and -0.0421 with 95% confidence for the native born group, while the true indirect effect lies between -0.1434 and 0.0595 with 95% confidence for the foreign-born group. Because zero is not in the 95% confidence interval for the native born group, the indirect effect

Table 7 Bootstrap Result for Mediation Model Test by Nativity.

| Native-born black PLWHA | | | | | | |
|--|--------|-------|---------------|---------------|----------|----------|
| BOOTSTRAP RESULTS FOR INDIRECT EFFECT | | | | | | |
| | Mean | s.e. | LL 95 CI | UL 95 CI | LL 99 CI | UL 99 CI |
| Effect | -.1202 | .0431 | -.2140 | -.0421 | -.2487 | -.0230 |
| SAMPLE SIZE | 63 | | | | | |
| NUMBER OF BOOTSTRAP RESAMPLES | 1000 | | | | | |
| Foreign-born black PLWHA | | | | | | |
| BOOTSTRAP RESULTS FOR INDIRECT EFFECT | | | | | | |
| | Mean | s.e. | LL 95 CI | UL 95 CI | LL 99 CI | UL 99 CI |
| Effect | -.0368 | .0515 | -.1434 | .0595 | -.1872 | .0916 |
| SAMPLE SIZE | 37 | | | | | |
| NUMBER OF BOOTSTRAP RESAMPLES | 1000 | | | | | |

of HIV-related stigma on mental summary score of HRQoL through avoidance coping strategy was significant for this group. The 95% confidence interval for the foreign-born group includes zero. The indirect effect of HIV-related stigma on mental summary scores of HRQoL through avoidance coping strategy was not significant for the foreign-born group.

Perceived Social Support as a Moderator

The subgroup approach was used to ascertain whether perceived availability of social support moderates the mediation effect of avoidance coping. Participants' scores were split into low and high levels of perceived social support group using a combination of median split method and stratification using nativity as grouping factor. Median split method divide a group in to two using the median value for the group and categorize participants who scored below the median value as low and those who scored above or equal to the median value as high. Native-

born and foreign-born groups were dichotomized separately using the median value within the group (83 for native-born group and 53 for foreign-born groups) to prevent over-representation of the group with higher mean in the high social support group and vice versa. If the median value for full sample (75) without consideration of the differences in the perceived social support scores between native and foreign-born groups were to be used, the high social support category would have consisted of 81% native-born participants and the findings would be confounded by nativity differences. Using a combination of median split and stratification by nativity is appropriate since the two groups significantly differ in their mean score of perceived social support.

Thus, for research question four, low social support categories were computed by merging the low social support categories within native-born participants and low social support categories within foreign-born participants in to low social support group. Low social support category stratified by nativity consisted of 60% native-born and 40% foreign-born participants. The final high social support categories were computed by merging the high social support categories within native-born participants and high social support categories within foreign-born participants in to high social support group. High social support category stratified by nativity consisted of 66% native-born and 34% foreign-born participants. Preacher and Hayes' (2004) SOBEL outputs were used to estimate the regression coefficient between the perceived HIV-related stigma on mental summary score of HRQoL and the bootstrapped indirect effect through the mediator avoidance coping for low and high social support groups.

The null hypotheses tested and respective findings for the research question four were:

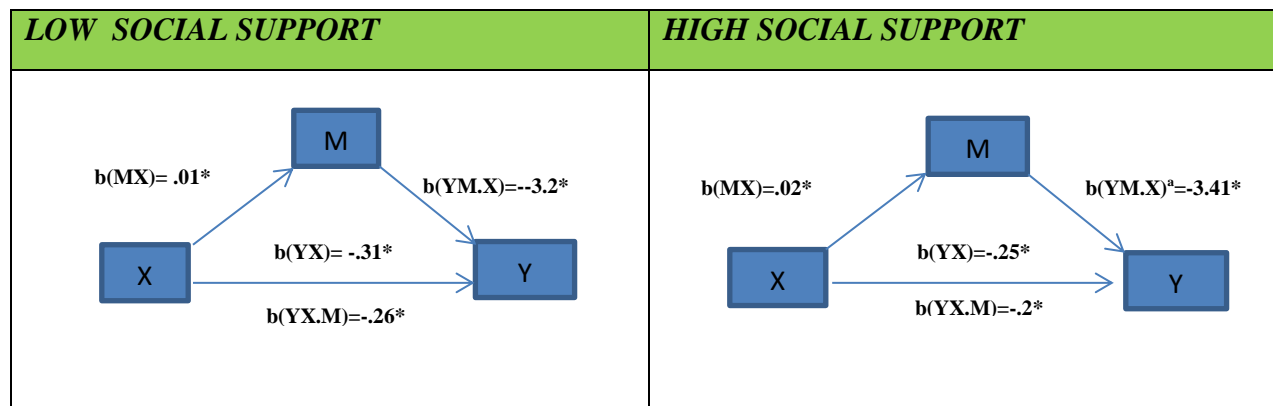


Figure 8 Regression Coefficients for Total, Direct and Indirect Paths by Social Support. X is perceived HIV-related stigma, M is avoidance coping and Y is mental summary scores of HRQoL. * $P < .05$ a = P value of .0499

Null Hypothesis 4-A: The relationship of perceived HIV-related stigma and mental summary score of HRQoL will not be moderated by level of perceived social support. There will be no difference between the mediation result between the groups that perceived low and high level of availability of social support.

Findings: The regression coefficients are depicted in Figure 8. The relationships between perceived HIV-related stigma(X) and mental summary scores of HRQoL(Y), $b(YX)$, are significant for both low and high social support groups. As the level of perceived HIV-related stigma increases, the mental summary scores of HRQoL decreases for both groups.

Null Hypothesis 4-B: Perceived social support does not moderate the indirect effect (the path between perceived HIV-related stigma and avoidance coping, and the path between avoidance coping and mental summary score of HRQoL). There will be no significant difference between the mediation result for the groups that perceived low and high level of availability of social support.

Table 8 Bootstrap Result for Mediation Model Test by Social Support.

| Low Social Support | | | | | | |
|---------------------------------------|--------|-------|---------------|---------------|----------|----------|
| BOOTSTRAP RESULTS FOR INDIRECT EFFECT | | | | | | |
| | Mean | s.e. | LL 95 CI | UL 95 CI | LL 99 CI | UL 99 CI |
| Effect | -.0485 | .0252 | -.1089 | -.0051 | -.1228 | .0097 |
| SAMPLE SIZE | | | | | | |
| | 50 | | | | | |
| NUMBER OF BOOTSTRAP RESAMPLES | | | | | | |
| | 1000 | | | | | |
| High Social Support | | | | | | |
| BOOTSTRAP RESULTS FOR INDIRECT EFFECT | | | | | | |
| | Mean | s.e. | LL 95 CI | UL 95 CI | LL 99 CI | UL 99 CI |
| Effect | -.0599 | .0446 | -.1644 | .0098 | -.2229 | .0330 |
| SAMPLE SIZE | | | | | | |
| | 50 | | | | | |
| NUMBER OF BOOTSTRAP RESAMPLES | | | | | | |
| | 1000 | | | | | |

Findings: The bootstrap output for indirect effects for both groups are depicted in Table 8.

The bias-corrected bootstrap 95% confidence interval estimated that the true indirect effect lies between -0.1089 and -0.0051 with 95% confidence for the low social support group, while the true indirect effect lies between -0.1644 and 0.0098 with 95% confidence for the high social support group. Because zero is not in the 95% confidence interval for the low social support group, the indirect effect of HIV-related stigma on mental summary score of HRQoL through avoidance coping strategy was significant for black PLWHA participants who reported low perceived level of social support. The 95% confidence interval for the high social support group includes zero. The indirect effect of HIV-related stigma on mental summary scores of HRQoL through avoidance coping strategy was not significant for black PLWHA participants who reported high perceived level of social support.

CHAPTER FIVE: DISCUSSION

This cross-sectional study was designed to examine the relationships among perceived HIV-related stigma, coping strategies, and health-related quality of life (HRQoL) among black/African American people living with HIV/AIDS (PLWHA) attending an early care HIV clinic. It is guided by the transactional model of stress and coping (TSC). The study explored HIV-related stigma as the major source of stress, factors associated with it and its relationship with the mental aspects of HRQoL among native and foreign-born black PLWHA.

This chapter is organized in the following sections: First, sample characteristics are discussed, starting with a description of the full sample characteristics followed by a comparison between native and foreign-born black PLWHA groups. Second, factors associated with the major study variables such as perceived HIV-related stigma, coping strategies, perceived social support, and health-related quality of life (HRQoL) are discussed. In this section, research question one that explored the differences between native-born and foreign-born blacks is discussed under each major variable. Third, findings for research question two related to whether avoidance coping mediates the relationship between HIV-related stigma and mental summary score of HRQoL are discussed. Last, findings for research questions three and four related to whether HIV-related related stigma and coping process are moderated by nativity (native-born vs. foreign-born black PLWHA) and perceived availability of social support (low vs. high level of perceived social support) are discussed. Finally, the strengths and limitations of the study, with future research directions and implications of this research for public health educators, healthcare professionals, and policy makers are discussed.

Sample Characteristics

Overall Sample Characteristics

The study sample characteristic resembles the HIV/AIDS profile of Georgia, specifically for urban cities. According to the 2010 State profile of Ryan White HIV/AIDS programs, 77% of HIV infected individuals who received care through the program in Georgia were non-Hispanic African Americans and 67% had a household income below or equal to the Federal Poverty Level (HRSA, 2010). Participants in this study were all blacks, either African Americans or foreign-born. Consistent with the state profile, more than half (57%) of the sample was unemployed and 66% earn less than \$ 10,999 per year. Women represent about 33% of those with HIV/AIDS and made up 52% of this sample. Characteristics of the study sample are also consistent with a recent study conducted in the State of Georgia. The mean age for a sample of 489 men and 165 women living with HIV in Atlanta, Georgia was 45 years old and the majority were unemployed with 11 and 12 years of education, and had an annual income of \$10,000 or less (Kalichman et al., 2012).

The Ryan White Early Care, the clinic where participants were recruited, is an early intervention clinic that provides services to PLWHA with a CD4 count above 200 cells/ μ l and those families affected by HIV. PLWHA who have a CD4 count below 200 cells/ μ l, co-morbidities, and complications will be referred to an infectious disease program located at a different site for further management. The only exceptions are those individuals with a tuberculosis infection or a sexually transmitted disease which the Early Care Clinic is capable of managing. Those individuals referred to the infectious disease program for further management will be referred back to Early Care Clinic once their CD4 count and the overall health improve. Thus, the sample pool in this study also includes those who have been diagnosed with AIDS and were much sicker at some point. As indicated in the very wide range in the number of years since

tested HIV positive (1-31 years), the sample in this study is very heterogeneous in terms of experience living with HIV infection and status of their disease.

Another sample characteristic that needs to be highlighted is the fact that 92% of foreign-born black PLWHA in this study were from the region classified as sub-Saharan Africa, according to the World Health Organization/The Joint United Nations Programme on HIV/AIDS (UNAIDS). Almost half of them were born in Ethiopia. Similar to the foreign-born black sample in this study, Ashton et al. (2012) reported close to half of their east African participants were Ethiopians. Another study reported that up to 50% of diagnoses in blacks occurred among African-born individuals (both sub-Saharan and northern African-born) in some states (Kerani et al., 2008). However, data at the national level from 33 U.S. states indicated an equal split between African-born and Caribbean-born black PWLHA, with Ethiopians accounting for 12 % of African-born PLWHA (Johnson, Hu & Dean, 2010). Thus, findings and recommendations presented in this study should be utilized with consideration of the proportion of PLWHA from sub-Saharan African countries.

Correlation between Nativity and other Demographic Variables

Foreign-born participants in this study were more likely to be female and to identify themselves as heterosexual. This finding is consistent with other studies among black foreign-born PLWHA in the U.S. that found foreign-born black PLWHA more likely to be female, heterosexual, and whose HIV infection was attributable to high-risk heterosexual contact than native-born black PLWHA (Ashton et al., 2012; Johnson, Hu and Dean, 2010; Kerani et al., 2008). Charney (2008) assess the status of 26 HIV-infected refugee from war-torn countries , of whom 85% were black, compared to 25 non-black Puerto Rican and 33 mixed race native-born PLWHA and found that refugees were more likely to be female than Puerto Rican and native born PLWHA. Similar findings were found among foreign-born black PLWHA live in Canada

compared with native Canadian born PLWHA (Noh et al., 2012; Tulloch et al., 2012). Given more than half of African foreign-born populations were male in 2005 (Kent, 2007), this finding indicates the disproportionate impact of HIV infection among African-born women in the U.S.

The mean age of the overall sample was 42 years, which reflects the general aging of the population of HIV infected persons in the U.S. The present study did not reveal age differences between the two groups, which is consistent with Charney's (2008) study that found no difference in the mean age of HIV-infected refugee compared with Puerto Rican and native-born PLWHA. However, the present study appears inconsistent with other studies that compared foreign-born black PLWHA with native-born black PLWHA. Two recent studies in the U.S. found significantly larger proportion of diagnoses for native blacks with ages from 40 to 49 (Ashton et al., 2012) and among people aged 13 to 29 years (Johnson, Hu & Dean, 2010) compared to African-born blacks. However, Ashton et al. (2012) found a higher percentage of African-born PLWHA among people age 20 to 29 years than native black PLWHA. Both studies found a higher percentage of HIV diagnosis in foreign-born blacks among people aged 30 to 39 years than in native black individuals (Ashton et al., 2012; Johnson, Hu & Dean, 2010). Tulloch and her colleagues (2012) also found that Canadian-born PLWHA were significantly older than sub-Saharan African-born patients.

There are several reasons why findings in the age difference between native and foreign-born PLWHA is inconsistent. One reason could be the differences how age variable was treated; continuous versus categorical variables. Second, there is difference within foreign-born population depending on their reason for immigration, which might have implications in their age demographics. Refugees often come as a family, which could include various age groups while others (e.g., students or asylee) may not come with their family. Since most of foreign-

born individuals got tested as a requirement of immigration processing, the age at which they come to the United States does make differences. Overall, age differences between foreign-born and native black PLWHA is not as clear as the gender differences which was consistent across literature.

Surprisingly, foreign-born in the present study do not differ with their native black counterpart in their education, income and employment status. African-born immigrants living in metropolitan areas in general have more education, higher salaries, and are more likely to hold higher-status jobs than other foreign-born blacks (Kent, 2007) and studies have shown similar findings among HIV-infected Africans. For example, HIV-infected refugees in Charney's (2008) study were more likely employed and had higher level of education. Similarly, sub-Saharan African-born PLWHA in Canada were more likely to be employed than Canadian-born PLWHA (Tulloch et al., 2012). Even though the present study findings were not significant, they trend toward similar difference in which higher proportion of foreign-born black PLWHA had college level or higher education (56% versus 44%), were employed (46% versus 41%) and reported annual income level above \$11,000 (35% versus 33%) compared with native black PLWHA participants. Foreign-born black PLWHA in the present study were more likely to be non-smoker and drink no alcohol than native-born black PLWHA. Sub-Saharan African-born PLWHA in Canada were also more likely to be a non-smoker compared with Canadian-born PLWHA.

The disease status variables assessed were self-reported number of years since tested HIV positive, age at the time of first HIV-positive test, AIDS diagnosis, being on ART, number of years on ART, recalling CD4 count, and CD4 counts. Statistical differences between native and foreign-born black PLWHA were found only in the number of years since tested HIV positive

and having an AIDS diagnosis. As in the present study, Tulloch et al. (2012) found no difference in HIV medication experience between Canadian-born and sub-Saharan African-born PLWHA. Foreign-born black PLWHA in this study had significantly fewer years since tested HIV positive and were more likely to have an AIDS diagnosis. These findings are consistent with empirical evidence. Charney (2008) found that HIV-infected refugee had significantly lowered number of months since diagnosed with HIV infection compared to Puerto Rican and native-born PLWHA. Page et al. (2009) also reported that black Africans were more likely to present with an AIDS diagnosis compared to both native-born blacks and non-blacks. Tulloch and her colleagues (2012) also reported that sub-Saharan African-born PLWHA had fewer years since HIV diagnosis compared with Canadian-born PLWHA. These findings support the evidence that foreign-born PLWHA, especially African, access care late and tend to have shorter number of years since tested HIV positive than other participants in several studies (Charney, 2008; Read, Emerson & Tarlov, 2005).

However, interpretation of self-reported responses specifically recalling of AIDS diagnosis and CD4 count may have measurement limitations and need to be considered cautiously. People might not remember their diagnosis or may not understand the differences between being diagnosed with AIDS vs. HIV. Only 63% of the study sample was able to recall their most recent CD4 count. Based on these responses, there was no difference between native and foreign-born samples in recalling CD4 count at the time of interview. This does not necessarily mean participants who did not recall their CD4 count in this study were not aware of their disease status or not engaged in self-management. It could be because of the timing of the interview, which often occurred prior to their discussion of current blood work with their physician. At the study clinic, CD4 count and viral-load are tested every three months followed

by a physician visit. Most of the interviews in this study occurred prior to or after the physician visit. Thus, this finding may be biased depending on whether participants were interviewed prior to or after the physician visit. Another explanation could be that participants in this study were asymptomatic, with high CD4 counts, and living a long time with HIV so they do not pay attention to the actual number of their CD4 count as long as they maintained a stable physical status and undetectable viral load. Yet, inability to remember or keep track of CD4 count should be concerning to HIV care providers as well as researchers. Future research should collect such data either from laboratory result reviews or blood samples to measure the actual values at the time of study rather than depending solely on verbal self-reports.

Another phenomenon is the absence of a significant difference in the CD4 count at the time interview while there was a significant difference in the AIDS diagnosis between native and foreign-born black PLWHA. This could be because the two groups were different in their initial CD4 count at the time of entry to care as foreign-born blacks often were found to enter care at an advanced disease stage compare to native black PLWHA (Crawford et al., 2012; Johnson, Hu & Dean, 2010). However, once foreign-born black PLWHA accessed HIV care, they progressed to AIDS at similar rates compared to native PLWHA (Page at al., 2009). That means, even though the two groups are different in their AIDS diagnosis, there is high possibility that their current CD4 counts showed no difference at the time of interview. This could also be as the result of the effectiveness of ART which increase and stabilize CD4 count overtime when taken appropriately. The overall similarities in the disease status between native and foreign-born black PLWHA in this study were also revealed in the analysis of physical summary score of HRQoL which will be discussed later.

Nativity and Associated Factors with Major Variables

HIV-related Stigma

Perceived level of HIV-related stigma was measured using a multidimensional measure of internalized HIV stigma scale (Sayles et al., 2008). This scale measures an individual's perception and experience of internalized HIV stigma in four areas: stereotypes, disclosure concerns, social relationships, and self-acceptance. The total score ranged from 2 to 98 with higher scores indicating higher level of stigma. This scale was originally evaluated in a diverse sample of 202 PLWHA in the U.S. in which African American/blacks were well represented (Sayles et al., 2008). The mean score for the overall perceived HIV/AIDS-related stigma for the present sample (53.71) was higher than the mean (41) Sayles and her colleagues (2008) found. The higher level of perceived HIV-related stigma in this study most likely is due to the higher proportion of foreign-born black PLWHA in the present study.

In the present study, foreign-born black PLWHA reported a significantly higher level of perceived HIV-related stigma than native-born black PLWHA. Significant differences between the two groups were also revealed in all four subscale scores such as stereotypes, disclosure concerns, social relationships, and self-acceptance. Though other researchers reported that African Americans/blacks reported higher levels of HIV/AIDS-related stigma than any of the other races (Sayles et al., 2008), no quantitative published study compared the difference between native and foreign-born black PLWHA living in the U.S. to the knowledge of the principal investigator. Quantitative researchers in other developed countries, however, reported that Caribbean PLWHA living in the U.K. (Anderson et. al. 2008), immigrants from high HIV endemic countries, living in Canada (Noh et al., 2012) face intense HIV-related stigma compared to native PLWHA live in the respective country. Sayles and her colleagues (2008) also found

that PLWHA who were not a native English speaker reported higher level of stigma. Several qualitative studies among foreign-born black PLWHA reported immense level of HIV-related stigma (Anderson et al., 2008; Dodds, 2006; Koku, 2010; Lawson et al., 2006; Ndirangu & Evans, 2009; Prost, 2005; Stutterheim et al., 2011). The present study's finding supports the hypothesis that the overall perceived HIV-related stigma significantly differs between native and foreign-born black PLWHA in which foreign-born black PLWHA reported a significantly higher level of perceived HIV-related stigma.

Stutterheim and her colleagues (2012) recently conducted semi-structured interviews to investigate whether the beliefs found to contribute to the stigmatization of European and North American PLWHA are also held by sub-Saharan African and Caribbean people living in Netherlands. They found that the beliefs that contribute to HIV-related stigma among the African and Caribbean communities are identical with what were found among native people. The belief that HIV is highly contagious and consequent fear of casual contact persists despite adequate knowledge regarding HIV transmission. This was found previously among the general population in the U.S (Kff, 2009) as well as African immigrant population (Beyene, 2000). Another belief contributing to higher HIV-related stigma among foreign-born black community, according to Stutterheim et al. (2012), was that HIV is a very severe disease associated with death and wasting. This is not surprising as most of foreign-born blacks came from countries where HIV medication for most part was difficult to get except recent immigrants who may have been exposed to recent changes in the anti-retroviral accessible. Previous negative experience with HIV infection, such as this, contributes to the fear among the general foreign-born population as well as foreign-born PLWHA.

Furthermore, foreign-born black PLWHA have immigration and acculturation processes that could be associated with higher perceived levels of stigma. Another possible explanation is perhaps foreign-born groups may have experienced additional stigma related to the community or neighborhood in which they lived or to the perceived notion that immigrants are the source of infection. Foreign-born populations also experience “layered or doubled” stigma because of other factors not directly related to their HIV status, such as immigration status (Darrow, Montanea & Gladwin, 2009; Nyblade, 2006; Reidpath & Chan, 2005). If healthcare providers become aware of the complexities of HIV-related stigma as perceived by foreign-born PLWHA, they will be more likely to develop culturally relevant programs to reduce HIV-related stigma in the course of providing healthcare.

In addition, among the foreign-born black PLWHA sample, perceived HIV-related stigma negatively correlates with the length of residency in the United States. As the number of years lived in the U.S. increases, perceived level of HIV-related stigma decreases. In addition to speaking and understanding English which was an inclusion criterion for this study, length of residency is considered the proxy for acculturation. The finding of this study is not consistent with a previous report among African-born black women and men attending a London HIV clinic where no relationship was found between perceived stigma and level of acculturation (Calin et al., 2007). It is important to note that acculturation is a complex concept and requires a more robust measure than what is used as a proxy in the present study. Thus, the relationship between perceived HIV-related stigma and length of residency in the U.S. should be interpreted very cautiously.

The present study’s findings with regard to the correlation of HIV-related stigma with age and sexual identity are consistent with other studies conducted among a diverse sample of

PLWHA from Wisconsin and New York City (Lee, Kochman & Sikkema, 2002) and among diverse sample of PLWHA from Los Angeles (Sayles et al., 2008). Consistent with the present study, both studies found no difference of HIV-related stigma by age and heterosexual PLWHA had higher levels of HIV/AIDS-related stigma than homosexual/bisexual PLWHA. Another study among 1,026 PLWHA living in Canada, of whom 19% were from high HIV-prevalence countries, also found that PLWHA who were lesbian/gay/bisexual) had a lower level of HIV-related stigma than heterosexuals (Loufty et al., 2012).

With regard to correlation of HIV-related stigma with gender, however, empirical evidence is mixed. In the present study, females had a significantly higher perceived HIV-related stigma than males, which is consistent with other studies (Carr & Gramling, 2004; Colbert et al., 2010; Lekas, Siegel, & Schrimshaw, 2006; Sandelowski, Lambe, &Barroso, 2004). On the other hand, both Lee and his colleagues (2002) and Sayles and her colleagues (2008) found no significant difference between HIV-related stigma and gender.

Another surprising finding of this study is the absence of significant correlation of perceived level of HIV-related stigma with other demographic variables such as income, education, and marital status. Contrary to the present study findings, Sayles and her colleagues found that the mean overall HIV-related stigma scores were significantly higher for PLWHA who reported income below federal poverty level, no or some high school education and being unmarried. This inconsistency may be the result of the differences in the gender, ethnic and foreign-born compositions of the samples. A meta-analysis of 24 articles conducted in North America also reported that HIV-related stigma was significantly and negatively correlated with income (Logie & Gadalla, 2009). As Logie & Gadalla (2009) described, there is a significant heterogeneity of HIV-related stigma and its correlates in the literature which is also evident in this study.

The findings show a correlation with stigma and disclosure: significantly higher level of HIV-related stigma among those who chose not to disclose compared to those who did disclose to at least one or more persons. Consistent with the present study, Charney (2008) found that HIV-positive refugee, non-white individuals, disclosed their HIV status to fewer people than Puerto Rican and native-born PLWHA living in Boston. Another study found that African-born black women and men attending a London HIV-clinic who had disclosed to nobody or just one individual reported greater overall perception of stigma than participants who had disclosed to two or more people (Calin et al., 2007). Empirical evidence suggests that fear of discrimination is a major reason for a lack of disclosure among African and Afro-Caribbean PLWHA (Stutterheim et. al., 2011). PLWHA perception of other's negative attitude is also known to cause low self-esteem and a feeling of shame which lead to fewer voluntary disclosure of HIV status (Aggleston & Parker, 2002; Bussel et al., 2008, Vance, 2006). Foreign-born black PLWHA not only report a significantly higher level of stigma, they also were more likely to report disclosing their status to nobody or very few people.

Researchers who assessed the outcome of disclosure, on the other hand, reported mixed outcomes. Disclosure could have either positive (more support) or negative (violence, stigma and discrimination) effects or both (Koku, 2010; Lee & Craft, 2002). Thus, interventions and patient care plans for foreign-born black PLWHA disclosing their status should consider all the possibilities depending on the patient's situation. Further research on the reasons and outcomes of status disclosure among foreign-born black PLWHA are also warranted.

Other factors that correlate with the overall perceived HIV-related stigma are being on ART and having an AIDS diagnosis. Results of the present study indicate that those individuals who reported taking ART and who have AIDS also reported a higher level of HIV-related

stigma. This finding is consistent with Makoae and her colleagues (2009) who report that being on ART increases the level of HIV-related stigma among international samples including PLWHA living in Africa. A possible explanation for this finding could be that those with AIDS, regardless of their current physical status, are more likely to have more symptoms than those without AIDS. This would make concealing the HIV status more difficult and stressful. Previous studies reported a significantly higher level of perceived HIV-related stigma among those PLWHA who reported greater severity of HIV symptoms (Lee, Kochman, & Sikkema, 2002). Similarly, PLWHA who are on ART consistently reported a higher level of HIV-related stigma because taking pills makes keeping HIV a secret harder and/or the effects from their medications provide a clue to others (Seigal & Schrimshaw, 2005). These findings are inconsistent with Sayles and her colleague's (2008) finding that the overall HIV-related stigma scores were not significantly associated with either a history of AIDS diagnosis or current ART medication. The only significant association they found was between social relationship subscale and a history of AIDS diagnosis. Sayles and her colleague's (2008) findings are also consistent with the present study in that HIV-related stigma scores were not associated with CD4 counts.

Perceived HIV-related stigma was also found to be associated with smoking and drinking alcohol. In the present study, PLWHA who smoke and drink alcohol reported a significantly lower level of perceived HIV-related stigma than non-smokers and non-drinkers of alcohol. This finding is consistent with Loefty et al.'s (2012) findings that drug users reported lower rates of stigma than non-drug users. The status of smoking and drinking was assessed using a yes and no question in both the present study and Loefty et al (2012) study, which does not address the frequency of smoking and drinking. Smoking and drinking behaviors that are infrequent and are used as socialization might indicate better social interaction and perceived fewer stigma, while

more frequent smoking and binge drinking can be indicators of emotional problems that perhaps aggravate or result from a perception of more stigma. Another explanation could be those who may have felt HIV was related to being immoral may also feel the same way about alcohol and smoking.

Coping Strategies

Coping with HIV-related stigma is conceptualized in the present study as a continuous process in which PLWHA attempt to manage HIV-related stigma and minimize its negative impact through cognitive and behavioral efforts called strategies. The Brief COPE measured 14 strategies which are categorized in to two major coping dimensions: approach and avoidance. Ways of measuring a coping strategy and classifying multiple strategies in to broader categories of approach and avoidance coping have been inconsistent across the literature. Researchers report a range of strategies used to cope with perceived HIV-related stigma (Makoae et al., 2008; Moskowitz et al., 2009) that could be influenced by cultural beliefs and values (Makoae et al., 2008; Wolitski et al., 2009).

In the present study, seven subscales (acceptance, active coping, planning, positive refraining, using emotional support, using instrumental support, and religion) were combined to measure adaptive coping. Five subscales (self-distraction, denial, substance use, behavioral disengagement, and self-blame) were combined to measure avoidance coping. These classifications were pre-determined in accordance with a large-scale metanalysis (Moskowitz et al., 2009) and other studies conducted among PLWHA. Approach and avoidance coping dimensions were constructed as an average of listed subscales under each dimensions (range between 2 to 8) and had satisfactory reliabilities (Cronbach α of .85 and Cronbach α .75, respectively) which is better than recent studies using the Brief COPE scales among PLWHA in

the U.S. (Pence et al., 2008) , immigrant PLWHA in Canada (Noh et al., 2012) , and HIV-positive pregnant women in South Africa (Kotze et al., 2013).

A study among 611 HIV-infected patients, of whom 69% were minorities, in five southeastern U.S. states using the Brief COPE categorized five subscales as adaptive (positive reframing, using emotional support, acceptance, religion, and active coping) and three subscales as maladaptive (denial, self-blame, and behavioral disengagement) reported Cronbach α 's of .74 and .72 respectively (Pence et al., 2008). A study among 259 adult HIV-infected immigrants in Canada categorized three subscales as adaptive (planning, positive reframing, and religion) and three subscales as maladaptive (venting, denial, and substance use) reported Cronbach α 's of .72 and .65 respectively (Noh et al., 2012). Another recent study among 224 HV-positive pregnant women in South Africa using slightly modified Brief COPE scale categorized eight subscales as active (acceptance, direct action, positive reframing, religion, emotional support, instrumental support, helping others and information seeking) and seven subscales as avoidant (distraction, escape, denial, emotional venting, feeling out-of-control, self-blame and substance use) and reported Cronbach α 's of .75 and .54 respectively (Kotze et al., 2013). Even if all these studies had used the Brief COPE measure, their differences in the classification and inclusion of subscales in two major dimensions of coping make direct comparison impossible.

The mean scores for approach coping (5.93, SD 1.08) and avoidance coping (3.61, SD 1.11) strategies are consistent with other studies. These mean scores are compared with the two studies used the Brief COPE scales among PLWHA in the U.S. (Pence et al., 2008) and immigrants PLWHA in Canada (Noh et al., 2012). Because of difference in the computation of the scales, the reported mean result converted to the percentile using the range provided in the respective study. The mean scores for approach and avoidance coping for Pence et al. (2008)

were 3.1 (possible range 1-4, at 70 % of possible range) and 1.5 (possible range 1-4, at 17 % of possible range) respectively. The mean scores for approach and avoidance coping for Noh et al. (2012) were 45.91 (possible range 16-64, at 38 % of possible range) and 22.50 (possible range 12-48, at 77% of possible range) respectively. For the present study, the mean scores for approach and avoidance coping were 5.93 (possible range 2-8, at 65 % of possible range) and 3.61 (possible range 2-8, at 27% of possible range) respectively. The finding of the present study resembles Pence and his colleagues' finding among diverse sample of PLWHA in the U.S. such that in general participants use more approach coping than avoidance. On the other hand, Noh et al. (2012) found among their immigrant PLWHA sample the opposite, in which their participants reported using more avoidance coping than approach coping strategies (35% vs. 77%). Approach and avoidance coping were uncorrelated in the presented study ($p = .45$) which is consistent with Pence et al.'s (2008) finding.

Among demographic characteristics, no gender difference was found for both the approach and avoidance coping strategies. This finding is consistent with other studies (Ashton et al., 2005; Vosvick et al., 2010). Other variables, such as age, having at least one child, smoking, number of years since tested HIV positive, and the number of years on ART showed significant correlations with avoidance coping. However, no significant correlation was observed between these variables and the approach coping strategies. In the present study, as the age and numbers of years since HIV diagnosis and years on ART increased, the use of avoidance coping strategies decreased. Participants who have at least one child and non-smokers reported greater use of avoidance coping than those who do not have children and do smoke. The older the person and the longer that person had lived with HIV, the lower their avoidance coping scores which could be because of their change in the experience and mastery of coping skills. Similarly,

PLWHA, especially immigrants, reported that having children caused them to use more avoidant coping as a protective measure to avoid stigmatization toward their family (Stutterheim et al., 2011).

Perceived Social Support

Social support is measured in terms of availability of social provisions. Social provision consists of the functional aspect of social support, which is the positive interaction and supportive actions within the social network. It is hypothesized that foreign-born black PLWHA will have a significantly lower level of perceived social support than native black PLWHA and that perceived social support moderates the relationships between HIV-related stigma, avoidance coping, and mental summary score of HRQoL. The present sample mean score of 67.07 ($SD = 25.64$) on the Medical Outcomes Study Social Support Survey (MOS-SSS) is, though slightly higher, consistent with other studies used MOS-SSS. The mean score for the overall perceived social support was 66.10 among infected African American women in the southeastern United States (Vyavaharkar et al., 2010) and 64.66 among HIV-infected adult immigrants in Canada (Noh et al., 2012).

Surprisingly, the only demographic variables that correlate with perceived level of social support were nativity and voluntary disclosure to at least one person. These showed a significant negative correlation. The present study finding that age and perceived social support had no correlation is inconsistent with past research among adults PWLHA in the U.S. (Heckman et al., 2002; Lovejoy et al., 2008) in which age had significant negative correlations with social support that is, as the age of the participant increased, the levels of social support decreased.

The findings of the present study is consistent with the non-statistically significant relationship that McDowell and Serovich (2007) found between demographic variables (race, sexual identity, education, relationship status and employment) and perceived social support in their sample of 125 women and 232 men with an HIV-positive or AIDS diagnosis in the U.S. Consistent with the present study, they reported no significant correlation between these variables and perceived social support. Only race had a significant association with the amount of available social support from family (McDowell & Serovich, 2007). Empirical evidence regarding the association of sexual identity and perceived social support however is mixed. Cooperman, Simoni, and Lockhart (2003) found a significant negative relationship between sexual orientation and social support, with lesbian/bisexual women reporting significantly greater social support from friends and groups/organizations than the heterosexual women in a non-probability sample of 373 HIV-positive, mostly African American and Puerto Rican, women in New York City.

Health-related Quality of Life

Researchers have identified stressful life events such as HIV-related stigma as factors affecting various dimensions of HRQoL. PLWHA who do not cope well with HIV-related stigma may have poor HRQoL and vice versa. PLWHA perceptions of stigma determine how it affects their health outcome as mediated by the coping strategy they use and their perception of the adequacy of resources available to them (Holzemer et al., 2009). Although biological factors such as the disease state, HIV symptoms, treatments, and co-morbidity are known to be related to HRQoL (Davis, 2004; Hansen et al., 2009; Holzemer et al., 2009; Spirig et al., 2005), the psychosocial stress that comes along with the illness also affects HRQoL. Portillo et. al. (2005) found that individual characteristics, environment, physiological factors, symptom status,

functional status, and general health perceptions contributed significantly to HRQoL in an ethnic minority sample of which 50 % were African Americans. Stressors such as HIV-related stigma, low self-esteem, shame, depression, lower social support, and medication non-adherence are also known to contribute to poorer HRQoL.

HRQoL was measured using the second version of Short Form health survey (SF-12v2). The mean physical and mental summary scores of HRQoL were 52.07 and 46.48. These are slightly higher than but consistent with the mean score of SF-12v2 physical and mental component scores (47.7 & 44.0, respectively) among 112 predominantly Caucasian men PLWHA sampled in Canada (Ion et al., 2011). However, the present study's findings were higher than the mean score of SF 12 physical and mental component summaries reported among low-income HIV infected adults who are on ART which are 41.0 and 41.9, respectively (Visiwanathan , Anderson & Thomas, 2005). This difference in mean scores may be a reflection of the varied characteristics of sample, the difference in the type of SF 12 scale (SF 12v1 vs. SF 12v2) used, and the disease status. The difference between the physical and mental summary scores of the present study is wider than the other studies which indicate that the present study's sample have higher physical summary scores of HRQoL. However, despite their stable physical health status, they exhibit poorer mental summary scores of HRQoL which is the focus of subsequent analysis.

The present study also differs from other studies with regard to the association between demographic variables and physical summary scores of HRQoL. The only consistent finding with past research among PLWHA (Heckman et al., 2002; Lovejoy et al., 2008) is that age showed a significant negative correlation with the physical summary score of HRQoL. As the age increased, the physical summary scores of HRQoL decreased. However, the present study found no correlation between age and the mental summary score of HRQoL.

In the present study, no gender difference was found in either the physical or mental summary score. This finding is also inconsistent with other studies that reported a strong relationship existed between gender and health-related quality of life, with women reporting lower levels of health-related quality of life than men (Mrus et al., 2005). The present study finding is also inconsistent with other studies with regard to sexual orientation. While no differences were found in either the physical or mental summary score based on sexual identity, a study conducted in the Netherlands among a sample of 7,076 participants reported a significant negative relationship between health-related quality of life and sexual orientation in which homosexual men but not lesbians had lower levels of HRQoL (Sandfort, deGraaf, & Bijl, 2003).

The findings on the physical summary scores of HRQoL did not support hypothesis 1-D. For the physical summary scores of HRQoL, foreign-born PLWHA actually reported a slightly higher but not statistically significant mean score than native-born black PLWHA (52.29 vs. 51.95). Even if the present study did not measure and compare HIV symptoms, the finding is inconsistent with a study among an international sample of PLWHA that found significantly fewer HIV symptoms among PLWHA living in Africa than Hispanic subjects residing in the U.S. (Holzemer et al., 2009). The present study also found no difference related to being on ART, knowing one's CD4 count, and the self-reported CD4 count. This indicates that psychosocial stresses perceived and experienced by foreign-born black PLWHA have more impact on their mental health status than the physical health status. There are reports that immigrant populations have better physical health than native populations with other chronic illnesses such as hypertension (Read, Emerson, & Tarlov, 2005).

The health profile of the foreign-born population in general is better than that of the native-born population. Immigrants exhibit longer life expectancies and lower overall mortality rates. Immigrants had lower prevalence of conditions such as hypertension, high cholesterol, cardiovascular disease, and asthma compared with native-born counterparts (Singh et al., 2006). This phenomenon is often referred as a healthy immigrant theory. The theory is that immigration often is not a random process and those who immigrate are healthier due to their specific characteristics that are favorable to positive health outcomes such as younger age, better levels of educational attainment, and correspondingly higher socioeconomic status compared to those they leave behind and compared to native born individuals. Other explanations are health selection through screening and the salmon bias. Health selection may result in part from the medical screening done before entry (Jasso, Rosenzweig & Smith , 2005). The salmon bias is the situation where those immigrants who are ill return to their home countries, resulting in a healthier group remaining in the U.S. (Palloni & Arias, 2004). Maintenance of healthy behavior associated with a traditional lifestyle such as healthier eating habits also mentioned in diet and nutrition related researches (Goel et al., 2004). Foreign-born population, however, do not exhibit better health for all chronic illnesses and disease situation. For example, compared to native born, immigrants experience higher mortality due to infectious diseases such as HIV and tuberculosis. This study provides further evidence that the difference in the physical health of native and foreign-born in the case of HIV/AIDS is different from other chronic illnesses.

The mental summary scores of HRQoL, however, did support hypothesis 1-D. Native-born black PLWHA report a significantly higher mean score than foreign-born black PLWHA. Though several researchers reported that African Americans/blacks reported lower levels of mental summary scores of HRQoL than any of the other races (Campsmith, Nakashima, &

Davidson , 2003), no quantitative published study compared the difference between native and foreign-born black PLWHA living in the U.S. to the knowledge of the principal investigator. Researchers in other developed countries, however, reported that Caribbean PLWHA living in the U.K. (Anderson et. al. 2008), immigrants from high HIV endemic countries and living in Canada (Noh et al., 2012) had lower mental summary scores of HRQoL than native PLWHA living in the respective countries.

Foreign-born black PLWHA face multiple influences of their infection and immigration related issues. Some of their issues are stigma, lack of social support, depression, domestic violence, cultural beliefs, legal status concerns, fear of the American health system, and linguistic difficulties. All those factors can affect their mental and emotional health (Koku, 2010; Shedlin et al., 2006). Even though, the study finding does not support the difference in physical summary scores of HRQoL as predicted, it does support the predicted difference in the mental summary scores of HRQoL between native and foreign-born black PLWHA. Foreign-born black PLWHA have a lower mental summary scores HRQoL compared to their native-born black counterparts. This study provides evidence that the two groups differ not only in their perception of HIV-related stigma and availability of social support but also with their mental summary scores of HRQoL.

Mediation Model

Although much is known about HIV-related stigma, avoidance coping strategies, and psychosocial outcomes such as depression, a review of the literature revealed a lack of understanding of the mechanisms through which these variables influence the mental summary score of HRQoL. There has not been a thorough assessment of possible paths in which they operate among the growing population of foreign-born black PLWHA. Understanding the

relationship between these variables from the perspectives of people living with HIV/AIDS is very important (Earnshaw & Chaudeoir, 2009). The second research question examined the relationships between HIV-related stigma, avoidance coping, and mental summary scores of HRQoL among native-born and foreign-born black PLWHA.

Perceived HIV-related Stigma and Mental Summary Scores of HRQoL

The issue of whether perceived HIV-related stigma was related to mental summary scores of HRQoL was proposed in the second research question hypothesis 2-A. The findings indicate that perceived HIV-related stigma indeed showed a significant negative correlation with mental summary scores of HRQoL. Those who perceive a higher level of HIV-related stigma had lower mental summary scores of HRQoL. This finding is consistent with other study findings reported by Holzemer et al. (2009) and Sayles et al. (2008).

A meta-analysis study reported significant relationships between perceived HIV-related stigma and poor mental health (Logie & Gadalla, 2009). Logie & Gadalla conducted meta-analysis of 24 articles in North America and reported that HIV-related stigma was significantly and negatively correlated with poorer mental health. Only four out of 24 articles reported to measure and assess the relationship between HIV-related stigma and QoL. Most of the articles focus on the relationship between HIV-related stigma and psychological morbidities specifically depression. The present study finding thus provides further evidence that perceived HIV-related stigma and the mental component of HRQoL have a significant inverse relationship among both native and foreign-born black PLWHA.

Avoidance Coping as a Mediator

Research question 2 also hypothesized (2-B) that the use of avoidance coping strategies mediates the relationship between perceived HIV-related stigma and the mental component of

HRQoL. Preacher and Hayes' (2004) robust bootstrapping method was used to test the mediated effect (also referred as an indirect effect). The findings support the hypothesis that use of avoidance coping strategy partially mediates the relationship between perceived level of HIV-related stigma and the mental summary score of HRQoL. Several researches identify avoidance or maladaptive coping as a mediator between stress and health outcome among African American HIV-infected individuals (Brincks, Feaster, & Mitrani, 2010). A recent study found that maladaptive coping strategy mediates between HIV-related stigma and depression among HIV-infected adult immigrants living in Canada (Noh et al., 2012).

Most of researchers so far have used the traditional causal step method and reached a binary conclusion (yes or no) on whether the use of avoidance coping mediates the relationship between HIV-related stigma and outcomes such as depression. One of the limitations with the casual method, Baron and Kenny (1986) method for example, is that it only identifies a complete mediation effect. Complete mediation effect occurs when the relationship between the predictor and the outcome change from significant when the mediator variable is included, to a non-significant relationship when the mediator variable is controlled. If the mediation effect is partial, the strength of the relationship between the predictor and the outcome is reduced when the mediator is controlled but stays significant in both situations. It is evident that if this study used casual method to test mediation, the mediation effect of the use of avoidance coping strategy couldn't be claimed according to the Baron and Kenny criteria. Researchers in previous studies recognized this limitation and recommended advanced mediation tests such as the Preacher and Hayes (2004) method in order to test the true mediation effect (Vyavaharkar et al., 2010).

In addition to the indirect effect test, Preacher and Hayes' (2004) method also produces the

traditional series of regression outputs between a predictor and a criterion. These regression results were used to assess paths between perceived HIV-related stigma, avoidance coping strategy, and mental summary of HRQoL. The present study findings support the hypothesis that as the level of perceived HIV-related stigma increases, the use of avoidance coping strategies increases. Also, as the use of avoidance coping strategy increases, the mental summary scores of HRQoL decreases. These findings are consistent with other empirical evidence. On one hand, studies indicated that HIV-related stigma was strongly associated with the use of avoidance (Kotze et al., 2013), and self-destructive coping strategies (Lee, Kochman, & Sikkema, 2002). On the other hand, there was a significant relationship between avoidance coping strategy and psychological well being (Moskowitz et al., 2009), isolation and increased symptoms of depression (Gore-Felton et al., 2006; Vyavaharkar et al., 2010), which in turn affected quality of life (Kalichman et al., 2002; Cohen et al., 2002). Finally, HIV-related stigma had a significant negative relationship with the mental summary scores of HRQoL controlling for the use of avoidance coping. This means that the perceived level of HIV-related stigma leads to a lower level of mental summary score of HRQoL, regardless of the difference in the use of avoidance coping. Thus, the use of avoidance coping strategies functions as a partial mediator between HIV-related stigma and mental summary scores of HRQoL.

Moderation Mediation Model

Nativity as a Moderator

As discussed above, there was a significant indirect relationship in which the change in the level of perceived HIV-related stigma was positively associated with the use of avoidance coping which, in turn, was negatively associated with the mental summary scores of HRQoL. Perceived HIV-related stigma also had an inverse effect on the mental summary score of HRQoL. In

research question three, it was hypothesized that these significant relationships would differ between native-born and foreign-born groups such that native-born groups would have weaker or absent indirect and direct effects than foreign-born groups.

It was predicted that the direct effect of perceived HIV-related stigma on the mental summary scores of HRQoL would be weaker or absent for native-born than foreign-born black PLWHA. Contrary to the expectation, this relationship was significant for both native and foreign-born groups. Hypothesis 3-A was not supported. As expected in hypothesis 2-B, the indirect effect differs between the native and foreign-born black PLWHA samples. The hypothesis that the indirect effect is weaker or absent for native-born than foreign-born black PLWHA, however, was not supported. In fact, the mediation effect of the use of avoidance coping strategy was significant for native-born black PLWHA while it was non-significant for foreign-born PLWHA. The mediation effect of avoidance coping among African American PLWHA is consistent with other studies (Brincks, Feaster, & Mitrani, 2010). In contrast, the finding among foreign-born black PLWHA indicated that the process in which perceived HIV-related stigma affect the mental component of HRQoL was not mediated through the use of avoidance coping strategies.

Additional finding is that the effect of perceived HIV-related stigma on mental summary scores of HRQoL, after controlling for avoidance coping, holds only for foreign-born PLWHA. Furthermore, there is a significant negative association between the use of avoidance coping and mental summary scores of HRQoL, after controlling HIV-related stigma, holds for only native-born group. The absence of a significant relationship between HIV-related stigma and mental summary scores of HRQoL when avoidance coping is controlled indicated complete mediation of the process for native-born black PLWHA. Non-significant relationship between avoidance

coping on the mental summary scores of HRQoL compared to native-born groups raise the question whether targeting to minimize the use of avoidance coping will help foreign-born PLWHA in the same way it work for native-born groups.

Although similar studies among foreign-born black PLWHA living in the U.S. were not found for comparison, the present study's finding is inconsistent with a recent Canadian study. A study among 259 HIV infected adult immigrants living in Canada found that the influence of stigma on depression was mediated by coping behaviors, however, these mediation effects were non-significant when examined in combination with mastery (Noh et al., 2012). Another study among HIV-infected African, Caribbean and black women in Ontario, Canada reported that the effect of HIV-related stigma on depression was partially mediated through resilient coping (Logie, James, Tharao, & Loufty, 2013). The influence of perceived HIV-related stigma on the mental component of HRQoL appears to be mediated by avoidance coping among the native born black PLWHA while there may be factors other than avoidance coping that mediate this relationship among foreign-born black PLWHA. Thus, the present study underscores the prominence of nativity, immigrant versus non-immigrant, in the relationship between perceived HIV-related stigma and the mental component of HRQoL.

Perceived Social Support as a Moderator

As discussed above, there was a significant indirect relationship in which the change in the level of perceived HIV-related stigma was positively associated with the use of avoidance coping which, in turn, was negatively associated with the mental summary scores of HRQoL. Perceived HIV-related stigma also had an inverse effect on the mental summary score of HRQoL. The present study hypothesized that these relationships would differ between the two categories of perceived level of social support availability. Perceived availability of social

support was divided into two categories using a median split to categorize the sample into high and low levels of perceived social support. The hypothesis was that black PLWHA who reported higher level of perceived social support would have weaker direct and indirect effects between perceived HIV-related stigma and the mental summary scores of HRQoL.

It was predicted that the direct effect of perceived HIV-related stigma on the mental summary scores of HRQoL would be weaker or absent for high social support group than low social support group. Contrary to the expectation, this relationship was significant for both low and high social support groups. Hypothesis 4-A was not supported. This finding is consistent with recent study among HIV-infected African, Caribbean and black women in Ontario, Canada reported that the effect of HIV-related stigma on depression was not moderated by social support (Logie, James, Tharao, & Loufty, 2013).

Hypothesis 4-B predicted that the direct effect of perceived HIV-related stigma on the mental summary scores of HRQoL would be weaker or absent for high social support group than low social support group. As expected, the indirect effect differs between low and high social support groups. This hypothesis was supported. The mediation effect of the use of avoidance coping strategy was significant for those black PLWHA who perceived lower level of social support availability while it was non-significant for those who perceived high level of social support availability. This finding is consistent with other study supporting the buffering effect of social support between stress and psychological outcomes among native black PLWHA (Lopez, Antoni, Fekete, & Penedo, 2012).

Although similar studies regarding the buffering effect of social support among foreign-born black PLWHA living in the U.S. were not found for comparison, the present study's finding is consistent with Noh and her colleagues (2012) recent study among 259 adult immigrant PLWHA

living in Canada. They found that social support is inversely related with depressive symptom severity. They also found a significant interaction between the stress levels and social support in the relationship between HIV symptom distress and depression. As in the case of coping strategy, the interaction of social support with HIV symptom distress become non-significant when the interaction of stress with mastery included in the model they tested (Noh et al., 2012).

The influence of perceived HIV-related stigma on the mental component of HRQoL, in this study sample, appears to be mediated by avoidance coping among the black PLWHA who preserved lower social support while the indirect effect of avoidance coping does not hold for those who perceived high level of social support. The existing evidence indicate that PLWHA who choose to disclose their status, seek help from others, and have a good social support system are able to deal with stigma-associated problems better than those who don't have such support (Colbert et al, 2010).

Summary and Conclusions

Despite its limitations, this study is unique and first in its type to compare native and foreign-born black PLWHA. This study provided no sufficient evidence that the two groups differ in their use of coping strategies (both approach and avoidance) and physical summary scores of HRQoL. The major findings provide sufficient evidence of differences between the two groups are summarized in three areas. First, there are differences in the demographic characteristics. Foreign-born black PLWHA were more likely to be female, heterosexual, a non-drinker of alcohol and a non-smoker, and to live with someone and not to voluntarily disclose their status. Foreign-born black PLWHA were also more likely to have AIDS diagnosis and fewer number of years since diagnosed with HIV infection. Second, foreign-born black PLWHA perceive significantly higher HIV-related stigma and lower social support availability and had lower mental summary scores of HRQoL compared to native black PLWHA. Third, unlike native-born black PLWHA, the use of avoidance coping strategy does not mediate the relationship between HIV-related stigma and the mental component of HRQoL among foreign-born black PLWHA. Finally, unlike black PLWHA who perceived lower level of social support, the use of avoidance coping strategy does not mediate the relationship between HIV-related stigma and the mental component of HRQoL among black PLWHA who perceived higher level of social support. Mediation and moderation findings are in line with the guiding theoretical framework. As synthesized in the transactional model of stress and coping, avoidance coping mediates the relationship between HIV-related stigma and the mental summary score of HRQoL while nativity and social support moderate the mediation effect of avoidance coping.

Strengths of the study

The present study had two major strengths. The first is that it is one of a few studies that examined HIV- related stigma, coping , social support, and HRQoL among foreign-born black PLWHA. They represent a significant but invisible proportion of those classified as African American individuals living with HIV, especially in places where African and Caribbean immigrants are concentrated. This study helps to identify the social factors that may contribute to the differences within the black community of PLWHA and assist health care professionals develop appropriate strategies to improve quality of life based on nativity.

Second, this study used very robust statistical methods. A growing literature and experts now advocate testing whether or not the size of the mediated effect (also referred as indirect effect) is significant instead of sole reliance on the traditional causal step method. Formal significance test of whether or not the size of the mediated effect is different from zero is the recommended state of the art method. Furthermore, bootstrapping method does not require the normal sample distribution assumption and is highly advocated to test the indirect effect in small sample studies. Thus, Preacher and Hayes (2004) bootstrapping method used to evaluate the significance of the mediation effect in this study is more robust and set this study apart from other studies.

Limitations of the study

Since this study employed a cross-sectional design, the causality between the variables cannot be determined. Although the study had enough sample size and power to detect a small to medium size effect, the foreign-born sample was the minimum needed and would not provide enough variability. The foreign-born black PLWHA participants in this study were predominantly from sub-Saharan African and would not represent all foreign-born black

PLWHA that often includes African and Caribbean born black PLWHA. So the findings cannot be generalized to all foreign-born black PLWHA in the United States. More systematic collection and presentation of country of origin data are required to fully describe the socio-demographic factor and consequences of HIV-related stigma within foreign-born black PLWHA residing in the United States.

There is also a possibility of response bias due to self-report. It is also possible that some PLWHA who did not utilize services offered by Early Care Clinic and did not speak English were automatically excluded from the study based on sampling and recruitment procedures. Some foreign-born PLWHA who otherwise might have met the inclusion criteria may also have refused to participate in the study due to fear of disclosure. Such selection bias limits the external validity of the study.

Not all findings and conclusions in this study are based on the bootstrapping method. Even if Preacher and Hayes (2004) bootstrapping methods used to test mediation, the series of regressions produced as a part of the Preacher and Hayes (2004) SOBEL output was used to detect the significance of single path between a predictor and a criterion variable such as paths between perceived HIV-related stigma, avoidance coping and the mental summary scores of HRQoL. These regression outputs were based on the normal distribution assumption. Thus, some of the analysis and discussion are based on the regression coefficients that assume normal distribution especially when analysis was conducted within native and foreign-born groups. In the future, researchers should use more advance mediation moderation test to solve such limitation.

Finally, this study focused only on HIV-related stigma, avoidance coping and social support as variables influencing mental component of HRQoL. It did not address other possible factors that might be related to mental summary scores of HRQoL such as depression, acculturation, and stigma related to other sources. Although most of the scales used in the present study have been tested and used at the international level, the Brief COPE scale has not been tested as much as the other scales. Using pre-determined dimensions of coping strategies also has inherent limitations as the subscales that are categorized under avoidance and approach coping strategies were not based on factor analysis in the actual study sample. These coping strategies influence results and their interpretation.

Research Directions

Information and resources have not accompanied the increasing number of foreign-born black PLWHA in the United States; thus, care providers have had to make their own adjustments to acquire new competencies often through professional networks. To the knowledge of the principal investigator, this study is the first to assess the relationship between perceived HIV-related stigma, avoidance coping, social support and mental component of HRQoL and compare native and foreign-born black PLWHA in the United States. The present study highlights significant differences and similarities between the two groups and provided the initial step towards developing a sound understanding of the growing population of foreign-born black PWLAH. A more extensive study that includes more psychosocial factors is recommended. For example, factors associated with acculturation, language, access to care, knowledge of the health care system, health seeking behaviors, resilience and approach coping, positive growth, and their contribution toward the quality of life and self-management of black PLWHA especially foreign-born groups should be studied further.

Implications

Public Health Implications

The present study raised several issues and has clinical as well as public health implications for designing future interventions to reduce the impact of HIV-related stigma and improve quality of life. The results underscore the importance of addressing HIV-related stigma, coping strategy and social support in the HIV care and case management provided to improve the overall quality of life. It is also important that the state and local health departments need to develop mechanisms to capture country of origin among PLWHA. Failure to identify country of origin may distort the true epidemiology of the epidemic and undermine the HIV/AIDS care needs of both native and foreign-born black PLWHA. The present study highlights specific areas where native and foreign-born PLWHA differ and identify specific points of interventions. Foreign-born black PLWHA are likely to require specific, culturally tailored and personalized efforts to reduce HIV-related stigma and its consequence.

Clinical Implications

Despite significant difference found in psychosocial factors such as living arrangement, smoking and drinking alcohol, disclosure HIV-status, stigma, social support, and mental summary score of HRQoL, no significant differences were found in the disease status indicators, coping strategy and physical summary score of HRQoL between native and foreign-born black PLWHA. Culturally sensitive case management services will be critical to address issues other than managing clinical symptoms among black PLWHA especially those who are new to the system and have different cultural background.

Furthermore, the two groups have no significance difference in their perception of tangible social support subscale while foreign-born perceive significantly lower support with

regard to other subscales such as affection, interaction and emotion/information subscales. This finding has clinical implications in that HIV care providers and care-givers must understand the critical role of social relationships in the management of foreign-born black PLWHA and understanding how these factors relate to HIV-related stigma and HRQoL as well as differ between native and foreign-born patients. Care provided must assess and understand the kind and quality of social support that would be available if needed.

It is also important to educate health care professionals regarding HIV-related stigma, related issues and their influence on prevention, care, treatment, and the overall quality of life of PLWHA. Health care professionals should make every effort to assess their HIV-infected patient's level of perceived HIV-related stigma and availability of social support and their way of coping in order to improve the quality of life of their clients.

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Appendix

IRB approvals

Emory University IRB approval

Page 1 of 2



EMORY
UNIVERSITY

Institutional Review Board

TO: Hanna Demeke
Principal Investigator
Graduate A&S

DATE: 13 June 2012

RE: **Expedited Approval**
IRB00057487
Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality of Life in People Living with HIV/AIDS

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory category[ies] F[7] as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 06/12/2012 and granted approval effective from **06/12/2012** through **06/11/2013**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Partial HIPAA waiver

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at www.irb.emory.edu, immediately, promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, study design, you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you

Julia Duckworth, MS
Research Protocol Analyst
This letter has been digitally signed

CC: There are no items to display
Holstad Marcia Nursing - Main

Georgia Department of Public Health IRB approval



Brenda Fitzgerald, MD, Commissioner

Nathan Deal, Governor

2 Peachtree St. NW, 15th Floor
Atlanta, Georgia 30303-3142
www.health.state.ga.us

Apr 30, 2012

Hanna Bewketu Demeke
Nurse Clinical Coordinator
688 Tom Smith Rd
Lilburn GA 30047

Project: 120402 - Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality of Life in People Living with HIV/AIDS

Project Status: Approved Until 04/30/2013

Dear Researcher,

The above-referenced project was reviewed by the DPH Institutional Review Board in accordance with expedited review procedures outlined in 45 CFR 46.110(b)(1), categories 7. The Board has **approved** this study until **04/30/2013**

If you wish to continue this project beyond the current approval period, please submit a "Continuing Review Application" before the above expiration date. If you do not submit a renewal application before the expiration date, the approval of your project will automatically terminate. Any involvement with human subjects must cease on the above date unless you have received approval from the Board to continue the project. It is the investigators responsibility to track the deadline.

This approval applies only to the protocol described in your application. IRB review and approval is required before implementing any changes in this project except where necessary to eliminate apparent immediate hazards to human subjects.

If you have any questions regarding this letter or general procedures, please contact the IRB Chair at lufedorowicz@dhr.state.ga.us. Please reference the project # in your communication.

Best wishes in your research endeavors,

Luke Fiedorowicz, Ph.D.

Digitally signed by Luke Fiedorowicz, Ph.D.
DN: cn=Luke Fiedorowicz, Ph.D., o=Georgia Department of Public Health,
ou=Institutional Review Board, email=lufedorowicz@dhr.state.ga.us, c=US
Date: 2012.04.30 10:40:40 -0400

DeKalb County Board of Health Site Permission



April 25, 2012

Institutional Review Board
Emory University
1599 Clifton Road, 5th Floor East
Atlanta, GA 30322

To Whom It May Concern:

Researchers at the Emory University Nell Hodgson Woodruff School of Nursing have requested permission to conduct the research project named below at the DeKalb County Board of Health Ryan White Early Care Clinic during the period of June 2012 to June 2013. This letter notifies you that I/we grant permission to research staff members of the Emory University Nell Hodgson Woodruff School of Nursing to conduct this research at the location listed below.

Research Project Title: Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality of Life in People Living with HIV/AIDS

Principal Investigator: Hanna B Demeke

Study Site Location: DeKalb County Board of Health Ryan White Early Care Clinic
445 Winn Way
Decatur GA 30030

Permission granted by:

S. Elizabeth Ford, M.D., M.B.A / Director DCBOH
Name of Individual (print) and Title

S. Elizabeth Ford
Name of Individual (Signature)

25 April 2012
Date

DeKalb County Board of Health
445 Winn Way – Box 987
Decatur, GA 30031
404.294.3700 • www.dekalbhealth.net

Recruitment Flyer

Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality of Life in People Living with HIV/AIDS

Volunteers Wanted for a Research Study

This research is being done to examine HIV-related stigma, coping strategies, social support and health-related quality of life among individuals living with HIV/AIDS. This will be done by asking individuals to recall their experience dealing with stigma, their general health and supports made available from their family and friends in the past one month.

Eligibility Criteria:

◆ *Infected with HIV* ◆ *18 years of age or older* ◆ *Identified self as African American or black* ◆ *Ability to speak English* ◆ *Mentally competent*

It is our hope that this research will benefit individuals living with HIV/AIDS by providing information and knowledge to HIV/AIDS care providers and policy makers.

Monetary compensation will be provided for participation.

Interview will be conducted at *DeKalb County board of Health Ryan White Early care clinic*

For more information or to participate

Please call Hanna Demeke at 404-906-4006

This research is conducted under the direction of Hanna Demeke RN, MSN, Doctoral Student and Dr. Marcia Holstad DSN, Associate professor at the Nell Hodgson Woodruff School of Nursing at Emory University.

Thank you and your participation will be appreciated!

Consent Form

Study No.: IRB00057487

Emory University IRB
IRB use only

Document Approved On: 6/12/2012
Project Approval Expires On: 6/11/2013

Emory University Consent to be a Research Subject

Title: Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality of Life in People Living with HIV/AIDS

Principal Investigator: Hanna Bewketu Demeke RN, MSN, Nell Hodgson Woodruff School of Nursing.

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.**

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview

The purpose of this study is to examine the relationships among HIV-related stigma, coping strategies, perceived social support and health-related quality of life among People Living with HIV/AIDS.

Procedures If you agree to be a part of this study, you will be asked questions about your HIV status, overall health, feeling and experience of HIV-related stigma and available support you have from friend and families. This interview will take about 30 minutes to complete. Interviews will be held at the DeKalb County Board of Health Ryan White Early Care clinic.

Risks and Discomforts

There are no risks of physical harm associated with this study. However, some of the questions may make you feel uncomfortable. You have the right to refuse to answer these questions. The main risk in this study is a break in confidentiality. To prevent breaks in confidentiality we, the researchers, will assign you a code number for the interview form. Your name and form will be kept in a separate locked cabinet. Only researchers will be able to look at your form. This information will be kept in a locked office. Your name will never be put on the interview form you complete. Your interview form will not be filed with your name.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about coping strategies to deal with HIV-related stigma and improve quality of life. The study results may be used to help others in the future.

Compensation

You will get \$ 15 if you complete interview. If you do not finish the study, you will get a partial compensation of \$10. Skipping questions that you do not wish to answer is not considered as incomplete.

Study No.: IRB00057487

Emory University IRB
IRB use only

Document Approved On: 6/12/2012
Project Approval Expires On: **6/11/2013**

Confidentiality

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board, the Emory Office of Research Compliance and Georgia Department of Public Health Institutional Review Board. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

Voluntary Participation and Withdrawal from the Study

You have the right to discontinue interview at any time without penalty. You may refuse to answer any questions you do not feel comfortable with, or you do not wish to answer. Decline to participate or withdraw from study will not affect your access to services provided at the DeKalb County Board of Health Ryan White Early Care clinic or elsewhere.

Contact Information

Contact Hanna Demeke at 404-906-4006:

- if you have any questions about this study or your part in it,
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu and Georgia Department of Public Health Institutional Review Board at 404-657-6645 or lufiedorowicz@dhr.state.ga.us

- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at <http://www.surveymonkey.com/s/6ZDMW75>.

Consent

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

Name of Subject

Signature of Subject

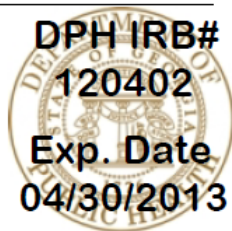
Date Time

Signature of Person Conducting Informed Consent Discussion

Date Time

Signature of Legally Authorized Representative

Date Time



Study Instruments

Demographic Questionnaire

Date: _____ Research ID _____

Instruction: This survey will begin by asking you questions about yourself. Please answer each question.

1. How old are you? _____ years
2. Were you born in the United States? ___ Yes ___ No If yes, Skip to Q5
3. Where were you born (Your country of origin)? _____
4. How long have you lived in the United States? _____ years
5. What is your gender? (Choose one) ___ Male ___ Female ___ Transgender
6. Which do you consider yourself to be? (Choose one)
 - a. ___ Straight, heterosexual
 - b. ___ Gay, homosexual
 - c. ___ Bisexual
 - d. ___ None of the above, unsure
 - e. ___ Refuse to Answer
7. What is that last grade or degree that you completed in school? (Choose one)
 - a. ___ None, I have not had any formal schooling
 - b. ___ Primary or Elementary School
 - c. ___ Junior High or Middle School
 - d. ___ High School or GED
 - e. ___ College or Technical School
 - f. ___ Graduate or Professional School
8. Are you currently married, separated, divorced, widowed, never been married, or in a committed relationship? (Choose one)
 - a. ___ Married
 - b. ___ Separated
 - c. ___ Divorced
 - d. ___ Widowed
 - e. ___ Never Been Married

- f. Committed Relationship
9. How many, if any, children do you have?
10. What is your current living arrangement? (Choose one)
- a. Living alone
- b. With family in the same house
- c. With other (non-family) in the same house
- d. In a group home or residence
- e. In a shelter
- f. No permanent residence (homeless)
11. What is your employment status?
- a. Employed full time
- b. Employed part time
- c. Unemployed
- d. On disability
12. What is your average annual income?
- a. \$ 0-10,999
- b. \$ 11,000-20,999
- c. \$ 21,000-30,999
- d. \$ 31,000-40,999
- e. \$ 41,000-50,999
- f. Over \$ 51,000
13. What is your religion?
- a. Christian
- b. Muslim
- c. Buddhist
- d. No religion
- e. Other _____
14. What year did you first test positive for H I V? _____yyyy
15. Have you ever been diagnosed as having AIDS? Yes No If no, Skip to Q 1
16. If you have AIDS, what year were you diagnosed as having AIDS? _____ yyyy

17. Are you on antiretroviral medication? Yes No If no, Skip to Q19
18. What year did you first start taking antiretroviral medication? _____ yyyy
19. Do you smoke? Yes No If no, Skip to Q23
20. What do you smoke? Cigarette Marijuana Both
21. How many cigarettes per day? _____
22. How often do you smoke Marijuana (per day)? _____
23. Do you drink? Yes, No If no, Skip to Q25
24. How many glasses/bottles do you drink per week? _____
25. Do you know your recent CD4 count? Yes No If no, Skip to Q 27
26. What was your recent CD4 count? _____
27. Have you ever told anyone about your HIV status? Yes No If no, Skip Q28
28. If yes, have you ever shared your HIV status with someone from any of the following groups? (Check all that apply)
 - a. sex partner
 - b. family member including children
 - c. church members,
 - d. others infected with HIV
 - e. health care provider,
 - f. coworker
 - g. employer/supervisor
 - h. other _____

HIV STIGMA SCALE

This study asks about some of the social and economical aspects of having HIV. There are no rights or wrong answers. Please do your best to answer each question.

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|--|------------------|----------------------|------------------|------------------|-----------------|
| Stereotypes | | | | | |
| 1. HIV is different than other diseases like cancer because people with HIV are judged | 0 | 1 | 2 | 3 | 4 |
| 2. People assume I have done something bad to get HIV | 0 | 1 | 2 | 3 | 4 |
| 3. Society looks down on people who have HIV | 0 | 1 | 2 | 3 | 4 |
| 4. People think that if you have HIV then you got what you deserve | 0 | 1 | 2 | 3 | 4 |
| 5. People blame me for having HIV | 0 | 1 | 2 | 3 | 4 |
| 6. People assume I slept around because I have HIV | 0 | 1 | 2 | 3 | 4 |
| 7. People think that if you have HIV you do not deserve to have children | 0 | 1 | 2 | 3 | 4 |
| 8. People are afraid to let someone with HIV adopt a child | 0 | 1 | 2 | 3 | 4 |
| 9. People think I am a bad person because I have HIV | 0 | 1 | 2 | 3 | 4 |
| 10. Medical providers assume people with HIV sleep around | 0 | 1 | 2 | 3 | 4 |
| 11. People lose their jobs because they have HIV | 0 | 1 | 2 | 3 | 4 |
| 12. People think you can't be a good parent if you have HIV | 0 | 1 | 2 | 3 | 4 |
| Disclosure Concerns | | | | | |
| 13. I am concerned if I go to the HIV clinic someone I know might see me | 0 | 1 | 2 | 3 | 4 |
| 14. I am concerned if I have physical changes from the HIV medicines people will know I have HIV | 0 | 1 | 2 | 3 | 4 |
| 15. I am concerned if I go to an AIDS organization someone I know might see me | 0 | 1 | 2 | 3 | 4 |
| 16. I am concerned people will find out I have HIV by looking at my medical paperwork | 0 | 1 | 2 | 3 | 4 |

| | | | | | |
|---|---|---|---|---|---|
| 17. I am concerned that if I am sick people I know will find out about my HIV | 0 | 1 | 2 | 3 | 4 |
| Social Relationships | | | | | |
| 18. Nurses and doctors treat people who have HIV as if they are contagious | 0 | 1 | 2 | 3 | 4 |
| 19. Nurses and doctors dislike caring for patients with HIV | 0 | 1 | 2 | 3 | 4 |
| 20. I feel abandoned by family members because I have HIV | 0 | 1 | 2 | 3 | 4 |
| 21. People treat me as less than human now that I have HIV | 0 | 1 | 2 | 3 | 4 |
| 22. People avoid me because I have HIV | 0 | 1 | 2 | 3 | 4 |
| 23. People I am close to are afraid they will catch HIV from me | 0 | 1 | 2 | 3 | 4 |
| 24. I feel like I am an outsider because I have HIV | 0 | 1 | 2 | 3 | 4 |
| Self-Acceptance | | | | | |
| 25. I feel ashamed to tell other people that I have HIV | 0 | 1 | 2 | 3 | 4 |
| 26. I am comfortable telling everyone I know that I have HIV * | 0 | 1 | 2 | 3 | 4 |
| 27. My family is comfortable talking about my HIV* | 0 | 1 | 2 | 3 | 4 |
| 28. It is important for a person to keep HIV a secret from co-workers | 0 | 1 | 2 | 3 | 4 |

Brief COPE

These items deal with ways you've been coping with HIV-related stigma in your life since you found out you are HIV positive. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says how much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

| | | | | |
|--|---|---|---|---|
| 1. I've been turning to work or other activities to take my mind off things. | 1 | 2 | 3 | 4 |
| 2. I've been concentrating my efforts on doing something about the situation I'm in. | 1 | 2 | 3 | 4 |
| 3. I've been saying to myself "this isn't real." | 1 | 2 | 3 | 4 |
| 4. I've been using alcohol or other drugs to make myself feel better. | 1 | 2 | 3 | 4 |
| 5. I've been getting emotional support from others. | 1 | 2 | 3 | 4 |
| 6. I've been giving up trying to deal with it. | 1 | 2 | 3 | 4 |
| 7. I've been taking action to try to make the situation better. | 1 | 2 | 3 | 4 |
| 8. I've been refusing to believe that it has happened. | 1 | 2 | 3 | 4 |
| 9. I've been saying things to let my unpleasant feelings escape. | 1 | 2 | 3 | 4 |
| 10. I've been getting help and advice from other people. | 1 | 2 | 3 | 4 |
| 11. I've been using alcohol or other drugs to help me get through it. | 1 | 2 | 3 | 4 |

| | | | | |
|--|---|---|---|---|
| 12. I've been trying to see it in a different light, to make it seem more positive. | 1 | 2 | 3 | 4 |
| 13. I've been criticizing myself. | 1 | 2 | 3 | 4 |
| 14. I've been trying to come up with a strategy about what to do. | 1 | 2 | 3 | 4 |
| 15. I've been getting comfort and understanding from someone. | 1 | 2 | 3 | 4 |
| 16. I've been giving up the attempt to cope. | 1 | 2 | 3 | 4 |
| 17. I've been looking for something good in what is happening. | 1 | 2 | 3 | 4 |
| 18. I've been making jokes about it. | 1 | 2 | 3 | 4 |
| 19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. | 1 | 2 | 3 | 4 |
| 20. I've been accepting the reality of the fact that it has happened. | 1 | 2 | 3 | 4 |
| 21. I've been expressing my negative feelings. | 1 | 2 | 3 | 4 |
| 22. I've been trying to find comfort in my religion or spiritual beliefs. | 1 | 2 | 3 | 4 |
| 23. I've been trying to get advice or help from other people about what to do. | 1 | 2 | 3 | 4 |
| 24. I've been learning to live with it. | 1 | 2 | 3 | 4 |
| 25. I've been thinking hard about what steps to take. | 1 | 2 | 3 | 4 |
| 26. I've been blaming myself for things that happened. | 1 | 2 | 3 | 4 |
| 27. I've been praying or meditating. | 1 | 2 | 3 | 4 |
| 28. . I've been making fun of the situation. | 1 | 2 | 3 | 4 |

Brief COPE Scales are computed as follows (with no reversals of coding):

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioral disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humor, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26

MOS-SSS

People sometimes look to others for companionship, assistance, or other type of support. How often is each of the following kinds of support available to you if you need it? Circle one number in each line.

| | None of the time | A little of the time | Som e of the time | Most of the time | All of the time |
|---|---------------------------|----------------------------------|----------------------------|---------------------------|--------------------------|
| Emotional/informational support | | | | | |
| 1. Someone you can count on to listen to you when you need to talk | 1 | 2 | 3 | 4 | 5 |
| 2. Someone to give you information to help you understand a situation | 1 | 2 | 3 | 4 | 5 |
| 3. Someone to give you good advice about a crisis | 1 | 2 | 3 | 4 | 5 |
| 4. Someone to confide in or talk to about yourself or your problems | 1 | 2 | 3 | 4 | 5 |
| 5. Someone whose advice you really want | 1 | 2 | 3 | 4 | 5 |
| 6. Someone to share your most private worries and fears with | 1 | 2 | 3 | 4 | 5 |
| 7. Someone to turn to for suggestions about how to deal with a personal problem | 1 | 2 | 3 | 4 | 5 |
| 8. Someone who understands your problems | 1 | 2 | 3 | 4 | 5 |
| Tangible support | | | | | |

| | | | | | |
|--|---|---|---|---|---|
| 9. Someone to help you if you were confined to bed | 1 | 2 | 3 | 4 | 5 |
| 10. Someone to take you to the doctor if you needed it | 1 | 2 | 3 | 4 | 5 |
| 11. Someone to prepare your meals if you were unable to do it yourself | 1 | 2 | 3 | 4 | 5 |
| 12. Someone to help with daily chores if you were sick | 1 | 2 | 3 | 4 | 5 |
| Affectionate support | | | | | |
| 13. Someone who shows you love and affection | 1 | 2 | 3 | 4 | 5 |
| 14. Someone to love and make you feel wanted | 1 | 2 | 3 | 4 | 5 |
| 15. Someone who hugs you | 1 | 2 | 3 | 4 | 5 |
| Positive social interaction | | | | | |
| 16. Someone to have a good time with | 1 | 2 | 3 | 4 | 5 |
| 17. Someone to get together with for relaxation | 1 | 2 | 3 | 4 | 5 |
| 18. Someone to do something enjoyable with | 1 | 2 | 3 | 4 | 5 |
| Additional item | 1 | 2 | 3 | 4 | 5 |
| 19. Someone to do things with to help you get your mind off things | 1 | 2 | 3 | 4 | 5 |

SF-12 Health Survey

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

| | | | | |
|---|---|--------------------------------------|--------------------------------------|--------------------------------------|
| <input type="checkbox"/> Excellent (1) | <input type="checkbox"/> Very good (2) | <input type="checkbox"/> Good (3) | <input type="checkbox"/> Fair (4) | <input type="checkbox"/> Poor (5) |
|---|---|--------------------------------------|--------------------------------------|--------------------------------------|

2. The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

| | Yes, limited a lot(1) | Yes, limited a little(2) | No, not limited at all(3) |
|--|-----------------------------|--------------------------------|---------------------------------|
| a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Climbing several flights of stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

| | All of the time (1) | Most of the time (2) | Some of the time (3) | A little of the time (4) | None of the time (5) |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Were limited in the kind of work or other activity | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

| | All of the time (1) | Most of the time (2) | Some of the time (3) | A little of the time (4) | None of the time (5) |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Accomplished less than you would like? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Didn't do work or other activities less carefully than usual? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

| | | | | |
|---|--|---|--|--|
| <input type="checkbox"/> Not at all (1) | <input type="checkbox"/> A little bit (2) | <input type="checkbox"/> Moderately(3) | <input type="checkbox"/> Quite a bit(4) | <input type="checkbox"/> Extremely(5) |
|---|--|---|--|--|

6. The following questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

| | All of the time (1) | Most of the time (2) | Some of the time (3) | A little of the time (4) | None of the time (5) |
|--|------------------------------|-------------------------------|-------------------------------|-----------------------------------|-------------------------------|
| a. have you felt calm and peaceful? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. did you have a lot of energy? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. have you felt downhearted and blue? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities, such as visiting with friends, relatives, etc.?

| | | | | |
|--|---|---|---|---|
| <input type="checkbox"/> All of the time (1) | <input type="checkbox"/> Most of the time (2) | <input type="checkbox"/> Some of the time (3) | <input type="checkbox"/> A little of the time (4) | <input type="checkbox"/> None of the time (5) |
|--|---|---|---|---|

Debriefing Form

Debriefing: Relationships between HIV-related Stigma, Coping, Social Support and Health-related Quality of Life in People Living with HIV/AIDS

The purpose of the study you just completed is to examine the relationships between perceived HIV-related stigma, coping strategies, social support and the process through which these factors affects their health-related quality of life. As the number of HIV positive patients possessing a range of cultural beliefs and backgrounds, it is essential for HIV care providers to understand that for the complexity of psychosocial factors, in addition to the differences in lifestyle, cultural beliefs, and ethnic experiences, affect health-related quality of life. Previous research in the field has shown that HIV-related stigma affected the overall quality of life of individuals living with HIV/AIDS. This is especially true for minorities such as African Americans and foreign-born individuals. We will examine the differences and similarities between native and foreign-born black PLWHA.

At the end of our study, we will publish and present our findings for health care providers and institutions that could benefit from our research findings. Your name and other facts that might point to you will not appear when we present this study or publish its results.

If you have questions about this study, please do not hesitate to contact the principal investigator, Hanna Demeke RN, MSN, at hbdemeke@dhr.state.ga.us or hdemeke@emory.edu. If you have concerns about the study, please contact the Department of Public Health Institutional Review Board Director and Chair, Dr. Luke Fiedorowicz at lufiedorowicz@dhr.state.ga.us or (404) 657-6645. You can also contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu.

Thank you for participating in our study!