EVALUATING THE ACCEPTABILITY AND FEASIBILITY OF A TELE-DELIVERED, MINDFULNESS-BASED COGNITIVE THERAPY INTERVENTION FOR AFRICAN AMERICAN WOMEN LIVING WITH HIV/AIDS IN GEORGIA

by

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(Under the Direction of Nathan B. Hansen)

ABSTRACT

People living with HIV/AIDS experience depression at higher rates than the general population. According to current literature in this area, AAWLWHA tend to have elevated depressive symptoms and also tend to be “silent” about those experiences. Therefore, depression among this group tends to go undiagnosed and untreated. No known interventions specifically address depression among this group. There is a need for evidence-based contextualized interventions specifically addressing depression among HIV-seropositive African American women. Project UPLIFT (UPLIFT), a mindfulness-based cognitive therapy intervention, has been used for both the prevention and treatment of depression among people with epilepsy. The intervention is delivered by phone, cost-effective, and easily adapted for other chronic illness populations. This program provides a novel opportunity for adaptation and evaluation - assessing its potential for improving the mental health of AAWLWHA. This dissertation research involves 1) conducting qualitative data collection via focus groups with both cis- and transgender AAWLWHA in Georgia, and expert review, 2) adapting UPLIFT
and related intervention materials, and 3) conducting open trials of UPLIFT with AAWLWHA in Georgia. The overall purpose of the project was to examine the intervention’s acceptability and feasibility with the target group. Minor modifications were made to UPLIFT following qualitative data analysis and information gained during expert review. These changes included modifying language, lowering the overall reading level of teaching content, the inclusion of additional screening criteria such as self-report of vision and hearing ability, modifying a mindfulness exercise, and assuring anonymity during UPLIFT phone sessions. Overall UPLIFT was found to be both acceptable and feasible for cisgender AAWLWHA. Cisgender women who participated in the UPLIFT trial had few to no concerns about the UPLIFT content, though there were concerns about session logistics unrelated to the UPLIFT intervention specifically. Contrastly, and despite high self-reported satisfaction with UPLIFT, process data revealed that the intervention might be less feasible in its current adapted form, for transgender AAWLWHA.

INDEX WORDS: HIV/AIDS, Tele-therapy, Depression, Mental Health, African American, Transgender, Mindfulness, Mindfulness-based Cognitive Therapy
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DEDICATION

To the good Lord above for his continued grace, mercy, and favor over my life. You have been my guiding light in the darkest places. It is because of you that I AM.

To my husband, Sgt. Telly Jones, for your commitment to me and to our family. You have been my rock throughout this PhD program. Thank you for making this work for us, and for always believing in me. There is NO way I could have done this without you. I love you, always and forever.

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Phinished,

Dr. Josalin J. Hunter-Jones, PhD, MSW, MPH, CHES
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CHAPTER 1
INTRODUCTION

Background

According to the Centers for Disease Control and Prevention (CDC), Georgia ranks fifth in the country for new HIV diagnoses. In 2015, CDC reported that of all racial/ethnic groups, African American women disproportionately represented approximately 64% of all new HIV infections among women in the U.S. A.

A recent study found a significant association of low CD4 count and poor antiretroviral therapy (ART) adherence with untreated depression, where 58% of the sample of African Americans living with HIV/AIDS exhibited elevated depressive symptoms (CES-D ≥ 16). (Amanor-Boadu et al., 2016). Approximately 20% to 40% of people living with HIV/AIDS (PLWHA) experience depression, as compared to 6% to 10% of the general population, (National Institute of Mental Health (U.S.)). In populations of PLWHA, depressive symptoms are related to stigma, social support, stress, trauma, HIV diagnosis as a traumatic stressor, shame, coping strategies, sexual abuse (both in childhood and adulthood), and anxiety (Bennett, Traub, Mace, Juarascio, & O’Hayer, 2015; Chaudoir et al., 2012; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2000; Persons, Kershaw, Sikkema, & Hansen, 2010; Simoni & Ng, 2000; Vyawaharkar et al., 2007). Additionally, in some samples of PLWHA, African American women experienced greater depression than other HIV-seropositive subpopulations (Moneyham, Sowell, Seals, & Demi, 2000). There is also evidence that African American women living with
HIV often do not receive appropriate or adequate depression treatment compared to other women living with HIV/AIDS (Cook et al., 2014; M. S. Miles, Holditch-Davis, Pedersen, Eron, & Schwartz, 2007; Moneyham et al., 2000).

A critical barrier to addressing the mental health of African American women living with HIV is a cultural “silence” among this group, particularly as it relates to mental health. “Silencing the self” is a theory that was developed to describe the tendency of African American women living with HIV (AAWLWHA) to resist disclosing the experience of depressive symptoms for fear of burdening the family, distracting from the responsibility to care for the family, and/or appearing “weak” (DeMarco & Lanier, 2014; Lanier & DeMarco, 2015). Despite this silence contributing to little knowledge about AAWLWHA mental health experience, research has at least characterized predictors and correlates of depression among African American women living with HIV; findings demonstrate the experience of depression in this group as particularly influenced by trauma histories, social support, family stress, and the importance of spirituality and spiritual wellbeing (Ball, Tannenbaum, Armistead, Maguen, & Group, 2002; Braxton, Lang, J, Wingood, & DiClemente, 2007; Brownley, Fallot, Wolfson Berley, & Himelhoch, 2015; Dalmida, Holstad, Diiorio, & Laderman, 2011, 2012; Johnson, Cunningham-Williams, & Cottler, 2003; Jones, Beach, Forehand, & Foster, 2003; Owens, 2003; Szapocznik et al., 2004; Whitehead, Hearn, & Burrell, 2014).

Despite knowledge of these correlates and the negative impact of depression on treatment adherence and retention in care, depression still tends to go undiagnosed, unaddressed, and untreated among these women (National Institute of Mental Health, 2002). Further, few interventions have been designed to address depression in this
group, and evidence-based psychosocial interventions addressing the unique needs of African American women living with HIV are urgently needed.

**Significance**

The increasing availability and efficacy of highly active anti-retroviral therapy (HAART) has allowed PLWH to live longer, fuller lives. However, psychological distress remains a serious issue and an important problem to address in PLWH. Among all types of psychological distress experienced by PLWH, depression is the most frequent mental disorder (National Institute of Mental Health, 2002). Furthermore, depression is associated with high HIV viral loads (Cook et al., 2006; Tsao, Dobalian, Moreau, & Dobalian, 2004; Valente, 2003), and has been shown to negatively impact adherence and retention to HIV-related care, risky sexual behavior, quality of life, and the overall survival of PLWH (Willie, Overstreet, Sullivan, Sikkema, & Hansen, 2015). Therefore, these outcomes are of particular concern for AAWLWH (AAWLWH), a group described in some studies as experiencing more psychological distress than other racial groups (M. S. Miles et al., 2007; Moneyham et al., 2000), yet less likely than other groups to seek and obtain mental health treatment (Cook et al., 2006; Waite, Brawner, & Gipson-Jones, 2008).

**Research Questions**

The objective of this research is to explore the psychosocial experiences of AAWLWH in Georgia, and to culturally contextualize and evaluate the acceptability and feasibility of a mindfulness-based, cognitive therapy (MBCT) intervention, Project UPLIFT or UPLIFT, for AAWLWH. This research will be guided by the following questions:
Research Question 1: How can UPLIFT be adapted to reduce psychological distress among African American women living with HIV or AIDS (AAWLWHA)?

1.1 What are the experiences of stress, anxiety, and depression among AAWLWHA?

1.2 What are ways that AAWLWHA women cope with such experiences?

1.3 How do AAWLWHA feel about or towards mindfulness-based interventions as a way of learning coping strategies and techniques for coping with distress?

1.4 What do women in this target group like and dislike about the components of the Project UPLIFT intervention presented?

1.5 In what ways might UPLIFT be modified to better accommodate the needs of AAWLWHA and co-morbid depression?

1.6 What are the best ways to recruit AAWLWHA for UPLIFT, an MBCT intervention?

Research Question 2: Is UPLIFT both acceptable and feasible for AAWLWHA in Georgia?

2.1 Is the UPLIFT intervention acceptable for this target group?

2.2 Is the UPLIFT intervention feasible for this target group?

2.3 Is there a reduction in depressive symptoms from pre- to post-test for women participating in Project UPLIFT?

2.4 Is there a reduction in anxiety symptoms from pre- to post-test for women participating in Project UPLIFT?
2.5 Is there a reduction in symptoms of stress from pre- to post-test for women participating in Project UPLIFT?

Contributions to Field and Innovation

The research guided by the aforementioned questions is expected to contribute to the literature base regarding stressors and contributors to depression, as well as experiences of depression among AAWLWHA in Georgia. Additionally, findings from this research will provide evidence for the acceptability and feasibility of an evidence-based intervention, Project UPLIFT, that has previously been found effective in improving the mental health of people living with epilepsy/seizure disorder (Thompson et al., 2015; Thompson et al., 2010). When completed, this will (1) be among one of the first studies to qualitatively explore the mental health experiences of African American women living with HIV in Georgia; (2) be the first study to use an MBCT program to address depression among African American women living with HIV; and (3) be the first study to evaluate the acceptability and feasibility of UPLIFT with HIV-seropositive individuals. This study is expected to provide evidence for the importance of assessing the preliminary efficacy of UPLIFT for this population, via randomized, controlled trial.
CHAPTER 2
LITERATURE REVIEW

Facilitators & Barriers: African American Women’s Health

African American women face a multitude of health disparities, being overrepresented across chronic conditions such as the incidence of obesity, diabetes, HIV/AIDS; morbidity and mortality in epilepsy; mortality during childbirth; heart disease, HIV/AIDS, breast cancer, and stroke; and in untreated mental illness (namely, depression), (CDC, 2015; U.S. Census Bureau, 2004); (Keppel, Pearcy, & Klein, 2004). This overrepresentation and bleak prognosis for most of the aforementioned conditions are most evident by comparing the morbidity and mortality of African American women to their non-Hispanic counterparts (CDC, MMWR, 2015). These disparities are a result of a conglomerate of intersecting factors that contribute to the landscape of illness and disease for African American women as a community.

Facilitators

Most research focused on health disparities among African American women in the United States focus on factors that hinder favorable health among this group. Although it is critical to recognize what barriers exist, it is equally key to recognize factors that may assist in improving health among this group.

Due to a lack of literature aimed to establish facilitators of health among African American women, these factors are best illustrated in studies focused on the primary and secondary prevention efforts of specific health conditions- all of which have been
expressly named above. Across chronic conditions, literature exploring health
disparities most frequently cited the following facilitators: 1) knowledge/education, and
2) social support. These facilitators of African American women’s health will be
expounded upon below:

   A. Knowledge

   A common finding particularly in qualitative research with African American
women is that women feel like more illness-related ‘knowledge’ would be conducive to
behavior change, in meeting both primary and secondary prevention goals towards
reducing health disparities. Knowledge defined by Webster’s Dictionary as “information,
understanding, or a skill that you get from experience or education” is a construct
described across multiple individual and interpersonal-level theoretical frameworks
utilized in the public health field. ‘Knowledge’ as a theoretical construct is often
described or implied as a necessary foundation for other mechanisms through which
behavior change often occurs. Theoretical frameworks that describe the influence of
‘knowledge’ explicitly as an essential element in the behavior change process include,
the Social Ecological Model, Social Cognitive Theory; and others implicitly, Health
Belief Model, Stages of Change Model, and the Information, Motivation Behavior Skills
Model to name a few (Glanz & Bishop, 2010). A desire for health knowledge and
education targeting for example, self-breast examinations and time-points for
mammography screenings, physical activity strategies, and healthy eating are lessons
learned through formative research towards behavioral interventions with this
community (Nies, Vollman, & Cook, 1999; Ogedegbe et al., 2005; Yeh et al., 2008). It
should be noted that trends in research on facilitators of improved health or the
reduction of health disparities among African American women tend to be consistent across health conditions. In other words, ‘knowledge’, specifically health education or disease-specific related ‘knowledge’, is a commonly cited facilitator of African American women’s health as it relates to diabetes, obesity, cancer, stroke, and heart disease. By observation in reviewing this literature, health conditions that tend to be more stigmatized emphasize the need for support more frequently and earnestly than the need for knowledge, to facilitate positive behavior change in health.

B. Social Support

Social support first conceptualized by Barrera, defined as “perceived interpersonal social needs and the fulfillment of those needs”, and types of social support include emotional support, instrumental/tangible support, informational support, and companionship support (M. Barrera, 1986; M. Barrera, Jr. & Ainlay, 1983). Social support can be provided by a diversity of resources and networks; for example, family, friends, peers, and healthcare providers. Literature across chronic conditions and illnesses cite ‘support’ as critical for the initiation and maintenance of healthy behaviors among African American women. Notably, perceived social support has been found to play perhaps an even more critical role in disease management and psychological wellbeing than actual support given. Studies exploring epilepsy found that family support was of grave concern to African American women (Chlebowy, Hood, & LaJoie, 2010; Edwards, 2006). One type of support that is uniquely significant for African Americans as it relates to health is faith-related support (Drayton-Brooks & White, 2004). Faith-related support will be discussed further as a barrier to African
American women’s health overall, as this variable serves as both a positive support tool
and a barrier to wellness among AAWLWHA.

Barriers

The body of research on barriers to African American women’s health is
substantially grander than that of facilitators, and while qualitative research typically
involves inquiries about both facilitators and barriers of health improvement for certain
conditions- behavioral interventions typically focus on addressing the latter. The
barriers to African American women’s health are rooted in a complicated “soup” of
factors that can be categorized into two main areas: 1) cultural factors, and 2)
environmental/structural factors. Those factors will be discussed below:

Cultural

A. Mistrust

In describing African Americans mistrust of the healthcare system, one
researcher defined cultural mistrust as “paranoia, in the form of mistrust, of whites due
to past and present experiences with racism and oppression” (Terrell & Terrell, 1981).
The historical context of African American mistrust in the healthcare system is rooted in
interactions and generational stories/messages of relationships with primarily
Caucasians. From slavery to the Tuskegee Experiment, there is often a general
assumption that Caucasians and/or the healthcare system as an institution (historically
dominated by Caucasian men) is not an ally to the African American community (Eiser
& Ellis, 2007; Rusert, 2009; Smith, 1999). This viewpoint has had a longstanding
impact on the engagement of African Americans, both men and women, with the
healthcare system and health research (Corbie-Smith, Thomas, Williams, & Moody-
Ayers, 1999; Moseley, Freed, Bullard, & Goold, 2007). This mistrust has been especially salient as it relates to mental healthcare and mental health treatment in the African American community (Whaley, 2001; Williams, Neighbors, & Jackson, 2003).

B. Expectations of the “Strong Black Woman”

In African American culture, the woman plays a prominent family role. African American women are often seen as the primary caretakers in the family, particularly for children in the household and sometimes in the extended family community. This reliance makes it difficult for women to feel comfortable, or even that they have the freedom or time to care for themselves when necessary. In addition to the pressure of providing for the family in ways that are often all-consuming, African American women are viewed in a community context as a misrepresentation of the societally-prescribed black woman’s identity if not “strong” and “self-reliant” (Mays, Caldwell, & Jackson, 1996). This identity has previously been explored as the “Superwoman Schema” in which African American women see adhering to this role as beneficial to protect themselves and family, but that it can also be detrimental to health in the embodiment of stress (Woods-Giscombe, 2010). This view also contributes to a reduction in the likelihood that African American woman will seek mental health services or treatment when needed (Mays et al., 1996; Neal-Barnett & Crowther, 2000).

The low likelihood of African American women to seek mental health services when needed is often further obstructed by religious ideals regarding the origin of mental health problems, and the expectation by this culture to rely on faith exclusively as a coping mechanism (Chapman & Steger, 2010; Holt, Clark, Debnam, & Roth, 2014; Neighbors, Musick, & Williams, 1998). Moreover, African American women feel more
strongly about not sharing “household issues” outside the household so to speak than Caucasian women (Alvidrez, 1999). This further supports the notion that anything going on on the “inside” should stay on the inside.

Environmental/Structural

**A. Socioeconomic Status**

African Americans in the U.S. are more impoverished than any racial/ethnic community. As a group, African Americans are of lower socio-economic status than other racial groups (U.S. Census Bureau); socioeconomic status generally encompasses education, income, and employment. African American communities being disproportionately impoverished, chiefly in Southern states, is often attributed to the sociopolitical climate that is often stimulated by racism and discrimination- ultimately, perpetuating health disparities (Krieger, Smith, Naishadham, Hartman, & Barbeau, 2005). Disparate socioeconomic factors additionally contribute to a lack of equal access to healthcare, health information, and health services for African American women (Bonney et al., 2012; Gary, Campbell, & Serlin, 1996).

**B. Racial/ethnic discrimination**

As a minority group, African Americans have experienced racial and ethnic discrimination dating back to slavery. Individual and collective experiences of discrimination have been noted to impact health-seeking behaviors of African Americans as a community (Krieger et al., 2005). This observation is not wholly attributed to either men or women, but impacts both genders. Structurally, discrimination, whether overt or covert, impacts access to health education, resources, and healthcare services as does socioeconomic factors (Williams et al., 2003).
Contributors to HIV Risk for African American Women Specifically

Although the modes of transmission for HIV/AIDS remain the same for all sero-negative individuals, some sociocultural and community-level factors present unique risk for African American women distinguished from other groups. The two risk factors that will be elaborated on are: a.) gender and power dynamics; and b.) unbalanced male: female sex ratios.

Gender and Power Dynamics

A strong body of literature supports the notion that African American women tend to be submissive, not necessarily in personality but often in communication and negotiation around sexual interaction, condom use, and implicit indications of partner concurrency. The Theory of Gender and Power introduced by Robert Connell discusses the way in which gender and power imbalances stimulate sexual inequality. The theory has three basic interlinked structures, namely (a) sexual division of labor, (b) sexual division of power, and (c) the structure of cathexis (affective attachments and social norms) (Connell, 2014). From a practical perspective, gender and power dynamics affect the authority women feel in making decisions over their own sexual behavior. This theory was adapted over time to explain how gender inequities and differences in expectations generate risk that negatively impact women’s health, particularly in the domain of sexual health (Wingood, Scd, & DiClemente, 2000), those mechanisms are illustrated in Fig 2.1 below.
Several behavioral interventions targeting HIV risk for African American women focus on empowerment, particularly in young women, to take their sexual health “into their own hands”. These interventions, namely HORIZONS, SISTA, AFIYA, and IMARA, are evidence-based interventions based on the Theory of Gender and Power, with a specific focus on teaching skills such as condom use, sexual communication, and condom negotiation (DiClemente & Wingood, 1995; DiClemente et al., 2009; DiClemente et al., 2014; Wingood et al., 2004; Wingood et al., 2013; Wingood et al., 2000). The goal of these theoretically framed interventions are to overcome some of the barriers that exist as it relates to gender and power dynamics. These dynamics are still
relevant for African American women who have been diagnosed with HIV or AIDS as they provide reference to strategies in reducing onward transmission to partners through safer sexual practices.

*Gender Ratio Imbalances*

Gender ratio imbalances in the African American community perpetuate the HIV epidemic among women (Pouget, Kershaw, Niccolai, Ickovics, & Blankenship, 2010). African American women who identify as heterosexual face structural barriers that impact decisions in the relationship and sexual partners that they choose. African Americans are more likely than other cultural groups to choose partners within their own racial group, that is, African American women tend to have African American men as partners (Adimora, Schoenbach, & Doherty, 2006; Cooper et al., 2016). With HIV/AIDS rates being highest in the African American community, this introduces an immense level of risk. Due to the alarming rates of homicide among black men and incarceration rates removing African American men from the community—women outnumber men in the community which impacts available African American men to be intimate with (Green et al., 2012).

Though it often goes unnoticed, imbalanced gender ratios have deleterious effects on the overall sexual health of African American women who often have partners that are not monogamous, who may or may not use drugs intravenously, and who may or may not have sexual intercourse with other African American women or men (Ferguson, Quinn, Eng, & Sandelowski, 2006). For example, in a multilevel, longitudinal study of public housing residents forced to relocate, participants who relocated to areas with less violent crime and better economic conditions, also experienced reductions in partner
risk for HIV and STIs. This reduction in risk is related to the likelihood of a reduction in exposure to indirect concurrency (the odds of having a partner that has at least one other partner), and relocating from communities where there is a more balanced gender ratio (Cooper et al., 2014).

Epidemiology of HIV/AIDS in African American Women

Today, there are more than 1.1 million people living with human immunodeficiency virus (HIV) in the United States. Each year in the U.S., there are approximately 50,000 new cases of HIV, according to the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention (CDC), 2011). In the year 2011, African Americans disproportionately represented more than half of new HIV diagnoses among all racial/ethnic groups (CDC, 2011). Further, African American women are disproportionately affected by HIV/AIDS, as they represent approximately 64% of all new HIV infections among women in the United States; this group has the second highest incidence of HIV by intersection of race and gender following African American men who have sex with men who represent the highest incidence of all groups by race and gender. Most HIV infections among African American women are due to heterosexual transmission (CDC, 2011).

The HIV continuum of care, previously called the treatment cascade, is a standard model of care and treatment utilization for PLWHA (PLWHA) highlighting movement across the continuum towards ultimately, a reduction in new HIV incidence. In accordance with the National HIV/AIDS Strategy, it is critical to evaluate the sustenance and attrition of PLWHA as they ideally transition through each of the stages along the continuum. This care model allows assessment of participation across 5 main
stages: diagnosis, linkage to care, retention in care, prescription of ART, and viral suppression. Among the population of people living with HIV in the U.S., the CDC estimates that approximately 86% have been diagnosed (14% are unaware of their status) with HIV. Of the 86% who are aware of their status, 40% are actively in care at any given time (indicating tremendous attrition from care following diagnosis); 37% have been prescribed ART by a healthcare provider, and finally, only 30% have actually achieved viral suppression (ONAP, 2013).

African Americans are more grimly represented in outcomes across the care continuum than other seropositive populations in the U.S. According to the National HIV Surveillance System and the nationwide Medical Monitoring Project, 2011 data demonstrated that 74.9% of African Americans living with HIV/AIDS are linked to care following diagnosis, 48% are actively in care, and 35% have achieved viral suppression. Though the numbers on retention and suppression are higher than national averages among all PLWHA, there are two main concerns regarding onward transmission in this community: 1) the number of African Americans with HIV/AIDS who are still unaware, and 2) the number linked to care, and their HIV risk behaviors. The high incidence rates of HIV among African American women (as illustrated by Figure 2 below), indicate there are still challenges uniquely experienced by this group, and that those who are not suppressed are still transmitting to others due to unmanaged HIV/AIDS. These unique challenges compound the barriers to general health experienced by all African American women, even those who are HIV seronegative.
Unique challenges of AAWLWHA

Living as an African American woman with HIV/AIDS invokes challenges of being a “triple” minority- an African American, a woman, and living with a highly stigmatized illness. There are numerous challenges unique to AAWLWHA; however, due to space limitations, only those cited most frequently in the literature will be described below: a) spirituality/religion, b) stigma, c) coping, and d) mental illness.

A. Spirituality/Religion

The church is a cornerstone of African American history and culture. Whether or not an individual identifies himself or herself as religious does not necessarily include nor exclude them from the impact of religious ideals woven throughout African American culture. These ideals are primarily rooted in Christianity, and have an impact on decision-making, health, and the coping behaviors of African Americans (Chapman...

Both spirituality and Christianity as religious practice have had a distinct presence since days of slavery where Africans utilized it as a means of survival. Religiosity and/or spirituality can often be a barrier to care, particularly as it relates to African American mental illness. A large number of studies have evaluated the impact that religiosity/spirituality plays in the lives of AAWLHWA. While some see God and prayer as sources of comfort, some literature supports that there are religious beliefs pinpointing the devil as the source of HIV/AIDS, HIV/AIDS as a punishment from God potentially for wrongdoing, a reason for not adhering to medication, and justification in conspiracy theories around HIV/AIDS not being ‘real’ (“HIV denialism”), (Kalichman, Eaton, & Cherry, 2010). Conversely, spirituality/religiosity can be a way to help women cope with living with chronic illness, but the role that religion may play in creating challenges for African American women in particular, to thrive with HIV/AIDS cannot be denied or ignored (Braxton et al., 2007; Dalmida, 2006; Dalmida et al., 2011, 2012; Grodensky et al., 2015; Maman, Cathcart, Burkhardt, Omba, & Behets, 2009; Yi et al., 2006).

B. Stigma

From a socio-ecological perspective, stigma is a prominent factor in hindering PLWHA from better overall health outcomes and quality of life. According to Merriam-Webster's Dictionary, stigma is “a set of negative and often unfair beliefs that a society or group of people have about something” and discrimination is defined as, “the practice
of unfairly treating a person or group of people differently from other people or groups of people”. Stigma regarding HIV/AIDS often include erroneous judgments about risky sexual behavior, promiscuity, and infidelity. Additionally, in some communities, stigma may influence gender and power dynamics making it difficult for some partners to take steps to protect themselves.

In addition to the role of stigma in relationships, discrimination stemming from stigmatizing beliefs may also contribute to less than ideal health and quality of life for AAWLWHA. AAWLWHA might experience stigma and discrimination as a result of a trifecta: being a racial minority, a woman, and living with a chronic illness; oftentimes this can be even further exacerbated by the experience of mental illness (Neal-Barnett & Crowther, 2000), a challenge that will be discussed more elaborately below.

Literature suggests that the compounding effects of co-occurring stigmas often create difficulty for HIV-positive women in thriving, and decreases their overall quality of life (Earnshaw, Bogart, Dovidio, & Williams, 2013; Earnshaw & Chaudoir, 2009; Earnshaw, Smith, et al., 2013), (Quinn et al., 2014). Stigma can often lead to employing disengagement and avoidance coping mechanisms that potentially spawn mental illness (Bennett, Hersh, Herres, & Foster, 2015). Further, HIV-related shame, a construct describing the experience of internalized stigma and evaluated in diverse samples of PLWHA, may impact African American women uniquely and needs further exploration with this vulnerable group (Bennett, Hersh, et al., 2015; Bennett, Traub, et al., 2015; Neufeld, Sikkema, Lee, Kochman, & Hansen, 2012; Persons et al., 2010).
C. Trauma and Coping

It is evident that AAWLWHA face numerous challenges. One of these challenges, not uncommon among other PLWHA, is a history of sexual abuse in childhood and/or adulthood. Furthermore, in some adults with HIV, this trauma, among other experiences such as HIV diagnosis, can cause symptoms of Post-Traumatic Stress Disorder (PTSD), (Brownley et al., 2015; Hilerio, Martínez, Zorrilla, & Torres, 2005; Nightingale, Sher, Mattson, Thilges, & Hansen, 2011; Sikkema, Hansen, Meade, Kochman, & Fox, 2009; Sikkema et al., 2004; Simoni & Ng, 2000; Tarakeshwar, Hansen, Kochman, Fox, & Sikkema, 2006). Such trauma as sexual abuse or PTSD may exacerbate emotional distress (Brownley et al., 2015; Sikkema et al., 2009; Simoni & Ng, 2000), ultimately increasing the likelihood of experiencing depression and/or anxiety.

One of very few studies exploring the stress experienced by AAWLWHA specifically identified sources of emotional distress, and commonly reported coping mechanisms among this group (M. S. Miles et al., 2007). Emotional distress most often contributing to mood states such as depression included personal factors such as social support, social conflict, and spirituality; and, worry about having HIV. As it relates to coping with emotional distress, there is considerable evidence that African American women tend to rely on informal support systems such as family, friends, and church members. Additionally, literature in this area conveys that problem-focused coping interacts with each stage of HIV illness and that African American women rely heavily on their spirituality in coping with living with HIV/AIDS and mental health issues more specifically (Ball et al., 2002; Biggar et al., 1999; Braxton et al., 2007).
D. Mental Illness

Depression is the most commonly reported mental illness in the United States. According to the National Institute for Mental Health, approximately 5 to 10% of the general population are depressed. As with other populations living with chronic illness, PLWHA (PLWHA) experience depression at rates much higher than the general population. Estimates of depression among PLWHA are as high as twice that of seronegative populations (National Institute of Mental Health (U.S.); Tsao et al., 2004). In addition to the unique stigma and discrimination related to multiple minority identities of being both African American and female, and religious ideals and spirituality contributing to a heavy reliance on faith, this group is especially vulnerable to depression (Moneyham et al., 2000). Findings from limited research on depression among AAWLWA demonstrate that correlates of depression among this group are family support and hassles, social support, spiritual well-being, sexual abuse both in childhood and adulthood. Many of these correlates are distinct from correlates of depression amongst other subpopulations of PLWHA, indicating the importance of evaluating and addressing the needs of AAWLWA, independent of other HIV-affected populations (Dalmida et al., 2011; Jones et al., 2003; McNair & Prather, 2004; M. S. Miles et al., 2007; Owens, 2003; Peltzer, Domian, & Teel, 2015; Vyawaharkar et al., 2011; Waite et al., 2008).

Despite few studies exploring depression specifically among this group, studies exploring diverse samples of PLWHA have found African American women to be more depressed than other normative groups (Moneyham et al., 2000). Furthermore, African American women with HIV/AIDS are less likely to receive adequate depression
treatment (Cook et al., 2006). Untreated depression has been noted to be associated with less care and medication adherence, and higher viral loads among PLWHA (National Institute of Mental Health, 2002). Therefore, AAWLWHA are a group of particular concern as it relates to the treatment of depression, among other psychosocial concerns.

HIV Behavioral Interventions for African American Women

Based on the evidence provided about the facilitators and barriers to African American health, the unique HIV risk of African American women, the high incidence of new infections among this group, and the unique challenges that African American women with HIV face, it is clear that behavioral interventions that utilize current knowledge about this population to address the mental health and psychosocial concerns of AAWLWHA are terribly needed. Behavioral interventions should provide knowledge about risk, incorporate messages of empowerment that help to overcome perceptions of stigma and structural/environmental factors as well as promote agency in one’s own sexual health. The most effective interventions will likely incorporate collective esteem through group participation, and opportunities to either build new support networks with other infected African American women OR empower women participating to garner support from their own networks. Messages that are components of psychosocial interventions should directly address how spirituality may be invoked as a form of support and to uplift, but should not offend those who identify as spiritual or religious.
Gaps in Literature for Health of AAWLWHA

Only one known behavioral intervention currently exists for AAWLWHA, and has been deemed a high impact prevention program by the CDC. WILLOW, a program adapted from the SISTA program, is a social-skills building and educational intervention targeting heterosexual African American women who are HIV-positive (Wingood et al., 2004). The intervention consists of four 4-hour sessions facilitated by two female facilitators and held in a community-based setting. The intervention focuses on increasing knowledge about STIs and HIV, communication skills, how to discern between healthy and abusive relationships; and teaches coping skills, condom use and negotiation skills, and how to establish and maintain support networks, while emphasizing gender pride. The intervention was evaluated for efficacy in an RCT of 366 African American seropositive women in Georgia and Alabama. Over 12 months, women in the intervention group reported fewer episodes of unprotected vaginal intercourse, an increase in the frequency of condom use during intercourse, a lower incidence of Chlamydia and Gonorrhea infections, greater HIV knowledge and condom use self-efficacy, more network members, fewer beliefs that condoms interfere with sex, and fewer partner-related barriers to condom use, as well as demonstrated greater skill in using condoms than those in the comparison control group (Wingood et al., 2004).

Despite the success of WILLOW in an efficacy trial, the intervention does not directly address mental health problems, particularly depression (along with other psychosocial issues) among seropositive African American women. It is hopeful that WIHS (Women’s Interagency HIV Study), encompassing the largest cohort of HIV-infected women with specific sites in the Southern region of the U.S., will help to inform needed interventions for HIV-infected African American women (Barkan et al., 1998).
There is a need for the development of new interventions that aim to reduce depressive symptoms and/or the adaptation of currently available evidence-based interventions used with other populations to be contextualized for use with AAWLWHA. Interventions such as WILLOW could potentially be adapted to include behavioral-based strategies to improve effectiveness and maintenance of skills taught. Furthermore, formative research still needs to be done to learn how to effectively intervene on the mental health of this group.

An Overview of Mindfulness-based Interventions

Among interventions that provide promise for addressing mental health among AAWLWHA, is mindfulness. Mindfulness is the practice of being intentionally attentive in the present moment, non-judgmentally. Mindfulness-based stress reduction (MBSR) incorporates techniques of learning to focus and calm oneself to better cope with stress, pain, or other effects of illness. Originally introduced by Jon Kabat-Zinn, MBSR often involves meditational exercises derived from Buddhist practice, bringing together mindfulness meditation and yoga. Typical mindfulness-based stress reduction programs include approximately 8-weeks of intensive sessions which meet on a weekly basis, in addition to an in-person retreat. (Kabat-Zinn, 2005; Kabat-Zinn, Lipworth, & Burney, 1985; Kabat-Zinn et al., 1992). Most mindfulness-based stress reduction programs have a common theoretical foundation of the Transactional Model of Stress and Coping.

Transactional Model of Stress and Coping

MBSR has a rich theoretical foundation to include three main theories as a basis. One of these theories is Lazarus and Folkman’s Transactional Model of Stress and Coping. As illustrated in figure 1, the Transactional Model of Stress and Coping
discusses the response to stressors as appraisals, in a continuous exchange between an individual and his/her environment (Folkman, 1984; Lazarus, 1974). The first appraisal usually relates to the examination of how someone perceives they will be impacted by a potential stressor and their responsibility in contributing to the stressor, as well as how relevant or severe the stressor’s potential consequences could be. The second appraisal relates to one’s perception of control over the outcomes, emotions, and ability to do something about the stressor. In other words, if someone views an event or experience as stressful, their second appraisal assesses what resources are available and whether and they are equipped to cope with that stressor. These appraisals drive the coping effort of an individual, therefore impacting the propensity for experiencing depression, anxiety, or related pain (Folkman, 1984). Evidence has demonstrated that mindfulness-based strategies impact appraisal by encouraging positive reappraisal and helping individuals gain skills to either appraise an event or experience as a non-stressor or feel more equipped with the resources to confront the stressor in a healthy manner (Garland, Gaylord, & Park, 2009).
MBSR has shown treatment efficacy across a variety of populations experiencing chronic physical conditions, and is the most frequently cited mindfulness-based intervention (MBI) to date (Carlson, 2012). Below is a review of MBIs for the treatment of depression, anxiety, and chronic pain, discussed individually, in PLWHA.

**Mindfulness-based Interventions for PLWHA**

**Depression**

The Diagnostic and Statistical Manual of Mental Disorders describes depression as the experience of symptoms such as feelings of sadness, emptiness, or hopelessness; diminished interest and pleasure in all or most activities; significant weight loss; insomnia or hypersomnia; psychomotor agitation or retardation; fatigue or loss of energy; feelings of worthlessness or excessive/inappropriate guilt; diminished ability to think or concentrate, or indecisiveness; and/or recurrent thoughts of death, recurrent suicidal ideation, attempt, or plan. Of all reported mental disorders, the most commonly
reported mental illness in the United States is depression. As noted previously, estimates of depression among PLWHA are as much as twice that of seronegative populations. Though MBIs are plentiful in use for reducing depression across other chronic diseases and conditions, few MBI interventions have been considered in reducing depression among PLWHA.

In 2012, the effectiveness of MBSR with HIV-seropositive gay men was evaluated by use of an RCT with 117 participants in Canada. The purpose of the study was to assess whether MBSR was effective in improving psychosocial functioning and quality of life of the participants enrolled. Upon enrollment, participants were expected to attend eight 3-hour weekly sessions and a one-day retreat, as well as engage in an hour or more of assigned homework during 6 days of the week. Regarding evaluation, all participants were assessed at 3 different time points completing pre-test, interim, and post-test assessments. At 6-month follow-up, both the MBSR and treatment-as-usual (TAU) groups experienced reductions in depression; however, there were greater significant differences in positive affect, avoidance, and depression in the MBSR group. These differences were correlated with an increase in mindfulness skills which is a critical finding in considering the overall use of these techniques for PLWHA (Gayner et al., 2012). This study is one that makes a substantial contribution to MBI research for PLWHA. While it appears that the intervention was successful in reducing depression among the intervention group, there was also a reduction among those in the TAU group. This might support a theory related to mental health intervention efforts, an attention response, or that simply being enrolled in a study might stimulate changes in psychosocial functioning. Although it was not a primary outcome of interest, it should be noted that anxiety was evaluated, and was inversely correlated with MBSR skills.
In 2012, Duncan et al. evaluated the efficacy of an MBSR intervention on the reduction of antiretroviral (ART) medication-related side effects, bother and stress related to these side effects, quality of life, and medication adherence among a sample of 76 participants who were actively taking ART (Duncan et al., 2012). Once enrolled, participants were randomized to either the intervention or waitlisted group. Study expectations were to attend 8 weekly sessions for 2.5 to 3 hours weekly with homework assignments on practicing mindfulness skills. Participants were assessed at 3 different time points: baseline, 3 month, and 6 month follow-up. At both 3 and 6-month follow-up, participants in the intervention group reported significantly less ART side effects than the wait-listed condition (WLC). Additionally, distress related to ART side effects were reduced in the intervention groups as compared to the WLC, (Duncan et al., 2012). As it relates to distress, there was a reduction in distress at both 3 and 6 months for both groups, although there was a greater reduction for the MBSR group at both time points. This was an evaluation of distress as it related to ART side effects. However, there were no significant differences found between the MBSR and WLC groups as it relates to depression. An impressive contribution of this study is the evaluation of the impact of MBSR techniques on improving the management of ART side effects, as well as reducing ART side effect-related psychological distress. This study likely foreshadows how the relationship between ART, medication adherence, and depression will be evaluated in future studies, especially considering that funders are becoming more interested in biopsychosocial interventions and outcomes. The study also included a diverse sample of participants to include African American men and women. However, the very small sample size limits the generalizability and applicability of the study.
A recent cross-sectional study examined the association between “dispositional” mindfulness on both the psychological and physical health of PLWHA. This exploration involved an adaptation of the stress and coping model (Folkman, 1984; Moskowitz et al., 2015) in the relationship between four specific domains of mindfulness: 1) acting with attention/awareness, 2) non-judging of inner experience, 3) observing, and 4) describing; as well as an evaluation of appraisal, positive and negative affect, coping, and other indicators of psychological well-being and physical health. A diverse sample of 175 individuals living with HIV or AIDS responded to measures in these areas. Study researchers found mindfulness to be inversely related to depression, stress appraisal, and negative affect, escape avoidance, and self-blame coping mechanisms; mindfulness was positively related to positive affect. Mediators to mindfulness and psychological well-being included perceived stress and negative affect. Though these study findings represent a cross-sectional secondary analysis from an MBSR intervention, it has positive implications for components of mindfulness and which mediation pathways represent substantial grounds for future research aiming to bridge the gap between MBIs and psychological distress, namely depression.

Anxiety

The Diagnostic and Statistical Manual of Mental Disorders describes anxiety as the experience of symptoms such as excessive worry; difficulty controlling worry; restlessness or feeling keyed up or on edge; being easily fatigued; difficulty concentrating or mind going blank; irritability; muscle tension; and/or sleep disturbance.
In a review of the literature, no MBIs were located that target anxiety specifically. Most measured anxiety as another indicator of psychological distress while focusing on depressive symptomology as a primary intervention outcome. Though rare, the following is a discussion of two cross-sectional studies that explored the impact of mindfulness on anxiety, where anxiety was specifically the main outcome of interest.

In 2009, Gonzalez and colleagues recruited 98 PLWHA who had participated in a previous study to complete questionnaires measuring anxiety, depression, and mindful awareness. Based on prior research suggesting that perceived stigma of HIV/AIDS was related to the propensity of PLWHA to employ disengagement coping strategies (Varni, Miller, McCuin, & Solomon, 2012), this research focused on the relationship between stigma related to HIV/AIDS, disengagement coping, and mindful awareness. As hypothesized, disengagement coping and HIV/AIDS stigma and then mindfulness awareness were positively and negatively associated with both depression and anxiety, respectively. Additionally, in hierarchical regression analyses, disengagement coping and HIV/AIDS stigma, and then the interaction between the two accounted for over 50% of the variance in anxiety scores measured by the Beck Anxiety Inventory (Beck, Epstein, Brown, & Steer, 1988; Gonzalez, Solomon, Zvolensky, & Miller, 2009).

In 2012, Gonzalez and colleagues conducted an additional cross-sectional study with 164 adults living with HIV/AIDS to examine the relationship between anxiety sensitivity/worry related to bodily sensations among PLWHA, and mindfulness awareness. As expected, anxiety sensitivity was positively related to body vigilance, while mindful attention was negatively related to anxiety arousal (Gonzalez, Zvolensky, Grover, & Parent, 2012). Concepts such as body vigilance and bodily sensations open the
door to the consideration of MBIs for their efficacy in treating or helping to subside receptiveness to chronic pain associated with the illness of HIV or AIDS.

Though this research is cross-sectional, given the lack of MBIs evaluated for efficacy in reducing anxiety symptoms, this research provides a foundation for the mechanisms by which coping styles among PLWHA interact with mindful awareness and psychological well-being.

**Chronic Pain**

Millions of Americans suffer from chronic pain. Defined by the American Chronic Pain Association as any pain that lasts a long time, with an average timeframe of at least six months, chronic pain has various sources. Symptoms of chronic pain may include mild to severe pain that does not disappear; pain that may be described as shooting, burning, aching, or electrical; and/or feelings of discomfort, soreness, tightness, or stiffness. Chronic pain can be initiated by trauma, an injury or infection. Others experience chronic pain with no identification of its source (ACPA, 2016). Chronic pain can be exacerbated by common experiences of depression, anxiety, or anger related to pain. Furthermore, people living with chronic illness such as HIV/AIDS commonly report the experience of chronic pain. Chronic pain can be especially difficult to manage (Almeida, Seal, & Clark, 2014; Jiao et al., 2016; Merlin et al., 2014).

MBIs, particularly utilizing MBSR techniques, have been suggested as growing areas of inquiry for its’ usefulness among non-pharmacologic methods of reducing pain and improving physical health across chronic conditions (Niazi & Niazi, 2011). A recent systematic review on chronic pain among PLWHA demonstrated a high prevalence ranging between 39-85% depending on the subpopulation of interest (Parker, Stein, &
Jelsma, 2014). To further complicate the already complex competing needs of PLWHA, chronic pain is difficult to treat due to problematic opioid use, medical co-morbidity, and the need to coordinate medication as to avoid co-medication toxicities (Almeida et al., 2014; Merlin, 2015). Only one published study to date has explored the possibility of MBIs for chronic pain in PLWHA (George, Wongmek, Kaku, Nmashie, & Robinson-Papp, 2015). Spawned from knowledge of the impact of mindfulness on one’s autonomic nervous system and HIV on one’s body awareness through interoception (the sense of the physiological condition of the body), a mixed methods, pilot RCT was conducted to evaluate the preliminary efficacy and feasibility of utilizing MBSR techniques in treating chronic pain among PLWHA (Craig, 2003; George et al., 2015). Because there was no previously published research in this area, qualitative data was key in assessing the needs of PLWHA as it relates to chronic pain. The study team enrolled individuals who were English-speaking, infected with HIV, and had experienced neuropathic or musculoskeletal pain in the past 3 months. The qualitative component of the study involved conducting focus groups with participants to learn of their experiences with chronic pain related to HIV, and their thoughts about mind-body treatments of chronic pain. The pilot RCT component of the study involved randomizing patients to one of two groups, either a standard 8-week MBSR intervention group or an 8-week control group where they were provided education related to HIV and chronic pain, and responses to many of the themes that emerged in the qualitative data previously collected. In analyses of focus group data, both the intervention and control groups most frequently discussed the theme of “community”, the importance of being supported in coping with HIV and chronic pain, and the enjoyment of participating in focus groups with others who had shared experiences with HIV and chronic pain. Furthermore, MBSR presented
during focus groups was observed as useful in enabling participants to relax and in helping to relieve pain; the control educational intervention was also presented but not found to be useful in the same manner. In analyses of the main outcomes for the RCT, participants in both the MBSR intervention group and the educational control group reported improvement on pain measures and stress, regardless of group assignment. However, at 3 month follow-up, MBSR intervention group participants had maintained practicing MBSR techniques and reported substantial decrease in the intensity of pain, while control group participants reported an increase in intensity of chronic pain (George et al., 2015).

As the first study evaluating MBSR for chronic pain among PLWHA, these findings support the need for the evaluation of MBSR in a larger scale efficacy trial. Researchers designing interventions in this area should focus on the importance of integrating social support and allowing for group interaction into MBSR strategies for the relief of pain associated with HIV.

Cognitive-behavioral-based Interventions for PLWHA

Depression

Cognitive behavioral therapy is a known best treatment for depression and prevention of relapse of depression. Often coupled with treatment by use of anti-depressants, cognitive behavioral therapy has long been admired as ‘best practice’ for depression, and is furthermore recognized as an effective treatment for clinically diagnosed depression. (Beck & Dozois, 2011). Expectedly, cognitive-behavioral interventions (CBIs) focusing on the “interactions of thoughts, feelings, and behaviors” have been widely used for improving mental health for over 40 years (Beck, 2005).
Despite evidence on cognitive-behavioral strategies for treating depression, research is sparse in cognitive-behavioral-based interventions for treating depression in PLWHA. One RCT published in 2009 analyzed the efficacy of CBIs for mental health and immune functioning among PLWHA (Crepaz et al., 2008). This review, focusing on controlled trials, found that HIV-positive individuals who participated in CBIs showed significant improvement in depression, anxiety, stress, and anger than non-CBI participants. Notably, though, across CBI trials, there was no evidence of long-term effectiveness of cognitive-behavioral skills on depression and anxiety (Crepaz et al., 2008). These findings reiterate, as many psychosocial interventions with PLWHA do, that coping with illness-related stress may require behavioral reinforcement or maintenance skills to prevent the relapse of depression. Given that eight years have passed since the release of this meta-analysis, the need is even more relevant since PLWHA have care options that allow for living longer lives.

CBT-AD (cognitive-behavioral therapy for medication adherence and depression) is a 10-session intervention including 5 modules: adherence training and overview of CBT, behavioral activation, cognitive restructuring, problem solving, and relaxation training. Utilizing qualitative methods as a part of an RCT using CBI techniques, specifically CBT-AD, 14 HIV-positive individuals were asked to complete exit interviews about the intervention (Berg, Raminani, Greer, Harwood, & Safren, 2008). The intervention monitored medication adherence by use of Medication Event Monitoring System electronic pill caps (also known as MEMS), and depression by use of the Beck Depression Inventory (Beck, Steer, Ball, & Ranieri, 1996), The RCT included individuals with comorbid HIV and depression, excluding those with comorbid active substance use. In these RCT trials, CBT-AD was efficacious in reducing depressive symptoms.
(Steven A Safren et al., 2004). Qualitative data collected in Berg’s study provided data on the utility and acceptability of the intervention from the participants’ perspectives. Participants felt that the intervention was effective in helping reduce their depression and improve medication adherence, helped them to feel more in control of their thoughts and behaviors, and that the 5 modules were useful. Additionally, participants stressed that the relationship that they had with the therapist (often called, therapeutic alliance) was critical to the effectiveness of the intervention (Berg et al., 2008; Stiles-Shields, Kwasny, Cai, & Mohr, 2014). Two subsequent studies with larger sample sizes explored the efficacy of CBT-AD among PLWHA and concluded that participation in CBT-AD intervention groups was related to significant reductions in depressive symptoms, and improvement in medication adherence than comparison groups that received enhanced treatment as usual (ETAU) (Steven A Safren et al., 2009; S. A. Safren et al., 2012). The latter of these studies recruited participants who had triply morbid HIV, depression, and self-reported history of drug use.

**Anxiety**

As with MBIs for PLWHA, many CBIs target depression as a primary outcome, and include anxiety as secondary outcomes. Those studies discussed in the section about depression included findings on CBI efficacy for anxiety as well. No studies were located that explicitly aimed to investigate the impact of CBI strategies on anxiety in PLWHA.

**Chronic Pain**

In 2003, one of the first studies observing the feasibility of CBT for neuropathic pain management among PLWHA was conducted (Evans, Fishman, Spielman, & Haley, 2003). Study participants were randomized to either a supportive psychotherapy
comparison group or a six-week CBT intervention group. Both groups indicated a reduction in pain, with greater reductions in pain experienced by the CBI groups. However, the study initially enrolled a total of 61 patients that were randomized to group, and only 33 patients completed the study (Evans et al., 2003). While findings suggest that CBIs might be efficacious in managing pain experienced by PLWHA, it also suggested the intervention as formatted was not very feasible. A study conducted in 2009 aimed to curb the high attrition rates observed in the previous Evans et al. study by offering a CBI program that integrated into patients’ primary care setting (Cucciare, Sorrell, & Trafton, 2009). Another goal of this research was to establish whether specific participant characteristics were associated with improvements in reported chronic pain. Sixty HIV-positive men and women were enrolled into the project; a single group design was utilized and every participant was offered participation in the 12-week CBI. Despite efforts to improve attendance by offering CBI in a primary care setting for PLWHA, attrition was still high with 71.7% of the sample attending at least 1 session and only 35% attending at least 6 sessions. One key finding from this study is that non-Caucasian patients that had higher baseline levels of pain-related anxiety responded best to treatment (Cucciare et al., 2009). A subsequent study conducted in 2012 evaluated a cognitive-behavioral therapy pain management intervention for PLWHA. Findings were similar to previous studies offering CBI for chronic pain management; while program session attendance was associated with improvements in pain intensity and functioning as well as related anxiety, less than 50% of patients attended all sessions making it difficult to evaluate a dose-response relationship.
HIV Secondary Prevention Tech-Delivered Strategies

Advancements in medications to slow the progression of HIV to AIDS, stall the replication of the virus, and improve the immune system of those living with HIV has transitioned many efforts from primary towards secondary prevention. With improvement of ART, prevention approaches now involve the management of HIV as a chronic condition, and minimizing forward transmission from seropositive to seronegative individuals.

Sexual Risk Reduction in Late-Middle to Older Adults Living with HIV/AIDS

A plethora of telephone-administered motivational interviewing (MI) interventions have been evaluated for reducing risky sexual behavior among PLWHAs. One study targeting risky sexual behavior among late-middle to older adults living with HIV/AIDS randomized participants to one of 3 arms: 1) a control group, 2) a group providing four MI telephone sessions, and 3) a group providing one MI telephone session. MI sessions were facilitated by therapists (masters-level clinical psychology trainees), and were modeled after two substance use MI intervention models (T. I. Lovejoy et al., 2011). The intervention sessions lasted an average of 40 to 50 minutes in each format. Results of the intervention study demonstrated that those who participated in the 4-session MI format engaged in less risky behavior than the control condition with treatment fidelity demonstrating influence on an even greater reduction in risk (T. I. Lovejoy et al., 2011). Subsequent interventions geared towards sexual risk reduction through the secondary benefits of MI to reduce depression, stress, and anxiety demonstrated similar results, and presented evidence for the potential in telephone-
administered mental health interventions in facilitating sexual risk reduction (T. I. Lovejoy, 2012), and sexual behavior change (Travis I Lovejoy, Heckman, & Team, 2014).

Mental Health Improvement across Subgroups of PLWHA

Psychological distress is evidenced to be highly associated with risky sexual behavior, adherence and HIV-related care, quality of life, higher viral load, and overall survival of PLWHA (Cook et al., 2006; Tsao et al., 2004; Valente, 2003; Willie et al., 2015). A large number of telephone-administered HIV secondary prevention interventions were evaluated based on mental health and psychosocial outcome measures, where sexual risk reduction was secondarily impacted based on untreated mental health effects; these interventions include diverse groups of PLWHA (Himelhoch et al., 2013; Kempf, Huang, Savage, & Safren, 2015; Ransom et al., 2008). By and large, telephone-administered HIV secondary prevention interventions have a consistent track record of demonstrating efficacy in reducing symptoms of depression and anxiety, and improving coping self-efficacy among PLWHA. Moreover, distance-delivered interventions with a mental health or psychosocial component have been noted as an innovative approach to HIV secondary prevention, and offer a novel approach to increasing access and reducing the stigma an individual might face in seeking care in-person (J. L. Brown & Diclemente, 2011).

Project UPLIFT: A mindfulness-cognitive behavioral therapy intervention

Literature supports that mindfulness-based therapies may be a promising avenue for intervening with comorbid HIV/AIDS diagnoses and co-occurring mental health disorders. Furthermore, a review of technology-delivered interventions for PLWHA
suggest that dissemination of such programs might be a necessary mode of delivery for vulnerable groups of PLWHA, (Kempf et al., 2015), such as AAWLWHA.

Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) is a mindfulness-based cognitive therapy (MBCT) intervention that has demonstrated efficacy in reducing stress, anxiety, and depressive symptoms in people with epilepsy and with cystic fibrosis (Thompson et al., 2015; Thompson et al., 2010; Walker, Obolensky, Dini, & Thompson, 2010). The intervention is evidence-based and cost-effective, delivered over 8 weekly sessions, and has in the past been administered remotely by telephone or the web. Due to the success of MBSR and MBCT interventions used with other HIV-seropositive populations,(Carlson, 2012; Creswell, Myers, Cole, & Irwin, 2009; Gonzalez-Garcia, Ferrer, Borras, Muñoz-Moreno, et al., 2013; Jam et al., 2010; Moskowitz et al., 2015; Riley & Kalichman, 2015; Robinson, Mathews, & Witek-Janusek, 2003; SeyedAlinaghi et al., 2012; Yang, Liu, Zhang, & Liu, 2015) and the successful adaptation of Project UPLIFT for other chronic disease populations (Thompson et al., 2015), the proposed research will address an important problem by adapting and evaluating an evidence-based tele-therapy intervention for the treatment of depression among a new target group.

MBCT, the basis of Project UPLIFT, draws from several empirically evaluated theories and treatment modalities. The first of several theoretical foundations that led to the development of MBCT is Barnard and Teasdale’s “Interacting Cognitive Systems” (ICS) theory (Barnard & Teasdale, 1991). ICS links depression and depression relapse to a person’s tendency to use one of two modes of mind: the “doing” mode or the “being” mode. The “doing” mode is driven by goals towards change when there is a discrepancy between how a person desires a situation to be and how the current situation truly is.
The “being” mode, in contrast, is not focused towards change but in accepting the present regardless of what it is. According to ICS, being able to transition from one mode to the next, as well as being meta-cognitively aware (being able to recognize negative thoughts as impermanent) – are characteristics of persons less likely to be depressed or to become recurrently depressed, (Barnard & Teasdale, 1991; John D Teasdale, 1993; John D Teasdale, Segal, & Williams, 1995; J. D. Teasdale et al., 2000) Segal and colleagues have also contributed to the development of MBCT by detailing how those who have once experienced major depression are more likely to have recurring depression as a result of negative thinking patterns that are distinct from those who have not experienced major depression (Segal & Walsh, 2015).

In addition, cognitive-behavioral therapy (CBT) is one of the two integrated tenets of MBCT. CBT is recognized as an effective treatment for clinically diagnosed depression (Beck & Dozois, 2011). The second integrated tenet of MBCT is mindfulness, a skills-based practice that involves heightened awareness of one’s thoughts or experiences. Mindfulness interventions, such as mindfulness-based stress reduction (MBSR), often involve meditational exercises derived from Buddhist practice, and had an influence on the development of MBCT.

As mentioned previously, MBSR is based on Lazarus and Folkman’s Theory of Transactional Model of Stress and Coping. The Transactional Model of Stress and Coping discusses the response to stressors as appraisals (Folkman, 1984; Lazarus,

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<td>7. How can I best take care of myself?</td>
<td>7. Pleasure and Reinforcement*</td>
</tr>
<tr>
<td>8. Using what has been learned in the future</td>
<td>8. Relapse Action Plans</td>
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1974). This theory is considered to have a substantial theoretical influence on MBCT, the basis of Project UPLIFT. The eight Project UPLIFT intervention sessions integrate the theoretical foundations and influences of ICS, MBSR, MBCT (as influenced by both mindfulness and cognitive behavioral therapy), and The Transactional Model of Stress and Coping as evident by the intervention session titles and related content (see Table 2.1).

A study conducted in 2010 to consider the use of mind-body interventions such as MBSR for African American women concluded that the health impacts of stress and strain might be curbed by the use of mindfulness techniques, and offered a promising avenue amongst behavioral interventions potentially available for this group (Woods-Giscombe & Black, 2010).

Adaptation and Evaluation Methods

This dissertation research’s primary focus is the adaptation and evaluation of Project UPLIFT, an MBCT intervention previously deemed effective for those living with epilepsy, for AAWLWHA.

One of the most cited, early definitions of “adaptation” of behavioral interventions comes from Everett Rogers, a communications expert, describing it as “the degree to which an innovation is changed or modified by a user in the process of its adoption and implementation” (Rogers, 1995). Though scarce, in the past 20 years following his work, there have been a few frameworks established to provide guidance in the adaptation of behavioral interventions, as well as redefining the essence of adaptation by both definition and process. In the realm of HIV research, literature often justifies the establishment of these guidelines as primarily an effort to provide
consistency in making decisions about the approach to the adaptation of evidence-based programs. Evidence-based programs or EBIs are those declared by Center for Disease Control and Prevention’ (CDC) as best practice interventions (McKleroy et al., 2006). Evidence-based interventions are identified as effective typically through the process of clinical trial evaluation. A pre-requisite step for clinical trial evaluation is adaptation.

Researchers began to find an increasing need for concrete adaptation guidelines in determining appropriate steps for utilizing EBIs in other contexts - across cultures, with other populations, across health conditions, using varying modes of delivery. A chronological review of the emergence of these guidelines, and the ways in which these guidelines are both integrative and influential one to another, will be discussed here. However, it should be noted that in public health, interventions are often adapted without critically evaluated what changes should be made. This further reiterates the need for adaptation guidelines. It could be argued that the literature in this area has followed a similar trend.

*Cultural Sensitivity: Two-Dimensional Model*

Through clinical trials, EBIs are typically first found to be efficacious and then later deemed effective in a very specific context, typically with a ‘specific’ population in a ‘specific’ environment addressing the ‘specific’ needs and conditions of that population. Therefore, in translating programs across cultures, it is critical that these interventions/programs are contextualized to meet the needs of the population for which the program is being delivered. Resnicow and colleagues devised a two-dimensional model of adaptation to address the need for attending to cultural sensitivity in translational research (Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999). As
implied in the title of the article, “Cultural sensitivity in public health: defined and
demystified”, cultural sensitivity is often discussed without specific details about what a
program looks like when cultural contextualization has actually been prioritized. The
authors define cultural sensitivity as:

“The extent to which ethnic/cultural characteristics, experiences, norms, values,
and beliefs of a target population as well as relevant historical, environmental,
and social forces are incorporated in the design, delivery, and evaluation of
targeted materials and programs. Culturally syntonic, culturally appropriate,
culturally consistent and culturally relevant are viewed as synonyms (Resnicow et
al., 1999).”

This definition is distinguished from Resnicow’s definition of cultural competence which
is defined as an individual’s ability to exercise interpersonal cultural sensitivity.
Therefore, culturally tailoring and adapting interventions and programs invoke
employing cultural sensitivity in that adaptation. For Resnicow, this involves potential
of modification in two main dimensions: 1) surface structure, and 2) deep structure.

Surface structure involves achieving an alignment between the materials and
messages given in an intervention or program with the cultural norms of the target
population. Surface structure adaptation might include, for example, changing pictures
included in an intervention manual to look more like the population for which the
intervention will be delivered, or utilizing peer-matched (individuals who appear similar
to the program participants in race, ethnicity, age, etc.). Oftentimes, surface structure
components are considered “superficial”, but should still be attended to as they affect
the acceptability of a program, even potentially at first glance (Resnicow et al., 1999).
Unlike surface structure, deep structure components of a program are a bit more elusive, and involve being knowledgeable about the sociocultural and environmental space in which a population exists. While surface structure may impact the likelihood that individuals might utilize a program or attend to particular intervention components, deep structure impacts the “acceptability” of these (Resnicow et al., 1999). Deep structure modification often requires ethnographic or formative work to assess cultural beliefs that may or may not present conflict in the delivery of intervention components. For example, religion (spirituality for some), plays a tremendous role in the African American community. In interventions that involve meditation or spiritual messages, it is critical to attend to how those messages might be received so as not to offend individuals of the African American community, or to have them reject the knowledge and skills being presented that could otherwise provide some benefit. In applying these principles, community-based participatory and/or formative research strategies are helpful in making meaningful and acceptable adaptations to interventions and programs. Cultural sensitivity considerations should be made prior to the innovation of new interventions and ideas, or the modification of an existing intervention for a new group or environment.

*Innovation-Decision Process Model*

The diffusion of innovations is a theory heavily cited in intervention research as one that describes the mechanisms by which an innovation is communicated over time across or through individuals in a particular social system (Rogers, 1995; Rogers Everett, 1995). The diffusion of innovations framework, defines “innovation” as an idea new to an individual and includes four main elements: 1) the innovation itself, 2)
communication channels, 3) time (this step encompasses the innovation-decision process model that will be described in further detail below), and 4) the social system or context in which the innovation or behavior will be performed (Rogers Everett, 1995).

There are five key characteristics that impact the rate of adoption, and duly influence intervention delivery, adoption, and adaptation as viewed in models that follow this early process innovation-decision model. They are:

1) Relative advantage- Regardless of objective advantage, individuals will consider whether adoption of an innovation or behavior is advantageous relative to their knowledge of all other existing options. The more relatively advantageous one perceives the innovation or behavior being presented, the faster he/she will adopt the innovation or behavior.

2) Compatibility- If the presentation of an innovation or behavior aligns with an individual/social system’s core beliefs, values, and norms, that innovation or behavior will be considered compatible. The farther away an innovation or behavior is from an individual’s core cultural norms and/or beliefs, the more incompatible that innovation or behavior will seem. Incompatibility challenges engrained socially constructed and long practiced traditions, which only slows the process of adoption for new innovation.

3) Complexity- Individuals and social systems are more likely to adopt an innovation or behavior if it is easily understood. The more complex it is to gain new knowledge or skills, the less likely individuals will engage the innovation or behavior. Therefore, the less complex, the more quickly it will be adopted.

4) Trialability- An innovation that is ready for ‘trial’ is one that an individual can easily adopt. If an individual is unsure of what an idea or behavior is concretely, and is
unable to readily practice that innovation/behavior if he/she so chooses, the slower one will be to adopt it.

5) Observability- It is beneficial when a potential adopter can directly observe the results of adopting an innovation or behavior. The more visible the desired results, the more quickly one will adopt that innovation or behavior. If there are models or examples of success when behaviors have been adopted, an individual will do so, with hopes of benefitting from similar results.

As discussed in the introduction to this section, repetitiously innovating new programs when there are existing EBIs is inefficient and at times irresponsible. Reducing that tendency among behavioral scientists supports the necessity of concrete adaptation guidelines. Before concrete guidelines were established, most adaptation decisions had been based on Rogers’ innovation-diffusion framework. The framework includes a 5-step innovation-decision model that implicitly includes adaptation, but does not explicitly indicate how to ‘adapt’ interventions. This 5 step process is integrated into the time phase of the diffusion of innovations theory, and are as follows: 1) knowledge; 2) persuasion; 3) decision; 4) implementation; and 5) confirmation (Rogers Everett, 1995). The steps in this process essentially describes the influences on the acceptance and adoption of the innovation presented, and will be thoroughly described below:

1) Knowledge- When achieved, the potential adopter has gained the knowledge and skills necessary to adopt the innovation or behavior presented; thoroughly comprehends the information that is provided, and is able to recall the information and utilize the innovation if the decision is made to do so.
2) Persuasion- In this stage, a potential adopter forms a favorable or unfavorable attitude about or towards the innovation/behavior. Essentially, the individual decides whether they ‘like’ or are drawn to the innovation/behavior. Furthermore, being persuaded in this context involves considering whether or not the environment supports the adoption of this innovation or behavior. This is a critical step in the decision-making process.

3) Decision- The ‘decision’ stage is one in which an individual chooses whether or not they plan to adopt an innovation or behavior. The intention to adopt might involve seeking new information about the innovation or behavior, and is distinguished from the innovators’ influence as it is self-directed interest. Rejection might include either active or passive rejection of the innovation or behavior defined by whether an individual engages in the activity temporarily and later decides to reject it OR rejects the behavior before ever considering adoption, respectively.

4) Implementation- This stage involves an individual adopting the innovation or behavior and utilizing it on a continuous basis. This stage might also involve continuing to pursue information about the new innovation or behavior, in an effort to learn more about how to maintain or continually engage in it.

5) Confirmation- The final stage of this framework involves an individual seeking information to confirm or validate whether or not they made a good choice by adopting or not adopting the innovation/behavior. It is possible that during this stage, a decision is reversed. This stage is critical because whether or not the innovation/behavior was adopted, validation will have a long-term effect on the relationship that the individual has with that innovation or behavior moving forward.
Additionally, as it relates to the ‘time’ step in the Diffusion of Innovations, the uptake of innovation is determined based on the rate of adoption. This conceptualization has demonstrated the substantial influence that ‘time’ has on the uptake of adapted interventions. According to Rogers, as illustrated in Figure 1, the innovativeness of a social system should be assessed by classification into one of 5 categories: (1) Innovators-the first 2.5% to adopt an innovation; (2) Early adopters-the next 13.5% of individuals to adopt an innovation, typically a more local group that has a great deal of opinion leadership in a social system; (3) the next 34% of individuals to adopt an innovation, this group typically directly proceeds adoption by the average member of a social system; (4) Late majority-the next 34% of individuals to adopt an innovation, this group typically directly follows adoption by the average member of a social system, and finally; (5) Laggards-the last 16% to adopt an innovation, this group typically has no opinion leadership. These principles of innovation and adoption have had a lasting impression on the world of intervention design and adaptation.

Center for Substance Abuse and Prevention Adaptation Guidelines

Following Rogers’ innovation-decision process model as a foundation for the adoption of innovations, it became clear that one of the most critical considerations of adaptation work was/is adapting an intervention for appropriateness, yet maintaining
fidelity to the *core elements* of the intervention. The Center for Substance Abuse and Prevention (CSAP) made the first valiant attempt at providing guidelines in maintaining this adaptation-fidelity balance; expectedly, the recommendations were related to substance abuse and prevention research, but helped propel a trajectory towards more concrete guidelines for adaptation (Backer, 2001).

Having a solid foundation in innovation of new ideas or programs and how those ideas diffuse (Rogers Everett, 1995), CSAP strived to give clarity to the importance of remaining faithful to the core elements of those programs even when adapted, and setting standards for how to achieve the fidelity/adaptation balance. CSAP defined *program fidelity* as, more or less, the fit between the original developer components of a prevention program and its' actual implementation in a particular setting. From a public health perspective, this might mean maintaining the components that are tied to theory while making culturally relevant modifications. Depending on the context, fidelity has sometimes been alternatively referred to as exposure, adherence, or integrity. *Program adaptation* was defined by CSAP as “deliberate or accidental modification of the program”. It is notable that their definition of adaptation includes modification of a program even if unintended. This definition represents evolution in how adaptation is conceptualized in translational research and will be noted in subsequent adaptation models presented in this dissertation paper. CSAP identified that adaptation can occur in the following ways: “(a) deletions or additions (enhancements) of program components; (b) modification in the nature of the components that are included; (c) changes in the manner and intensity of administration of program components called for in the program manual, curriculum, or core components analysis, or (d) cultural or other modifications required by local circumstances” (Backer, 2001).
Having established that adaptation can occur in one or more of the ways described above, the CSAP guidelines beg the following question, “How does one achieve balance between program fidelity and program adaptation?” It seems fairly obvious that it is important to contextualize an intervention or program in an appropriate manner which presumes that there are ways in which an intervention/program might be well-suited for one culture or group, but not necessarily the next. The effectiveness of a program lies somewhere in between the awareness that the core elements of a program (the ‘nuggets’ that are ideally transferrable) are what make an intervention successful, and what makes it relevant in its’ adapted context. There is work that needs to be done in diffusing and translating interventions and programs, lest the core elements will be delivered in inappropriate ways, and likely, found to be ineffective. The core elements of interventions and programs described by Backer as “the main ingredients to a recipe” are those elements that when stripped of cultural context must remain. The phenomenon of striving to achieve this has been referred to as a ‘tug-of-war’ as it relates to behavioral interventions (Bopp, Saunders, & Lattimore, 2013); a ‘push and pull’ of difficulty in achieving the balance between program fidelity and adaptation that CSAP formally addressed in these early guidelines. Below is a figure illustrating the nuances of balancing the two in adapting chronic disease interventions (Carvalho et al., 2013):
The model of maintaining the balance between fidelity and adaptation was examined by CSAP in recognizing the number of effective substance use prevention programs available that required evaluation. When used in different environments, it may be argued that adaptation will occur regardless, and that this should happen in a more systematic manner (Domenech Rodriguez, Baumann, & Schwartz, 2011). Here is the list of six guidelines outlined in the CSAP report for obtaining balance of both fidelity and adaptation: 1) Identify and understand the theory base behind the program; 2) Locate or conduct a core components analysis of the program; 3) Assess fidelity/adaptation concerns for the particular implementation site; 4) Consult as needed with the program developer; 5) Consult with the organization and/or community in which the implementation will take place; 6) Develop an overall implementation plan based on these inputs. The CSAP guidelines also provided supplementary insight on future directions for expanding further knowledge related to

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<th>Program implemented with...</th>
<th>Example Adaptations</th>
<th>Degree of Adaptation</th>
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| High fidelity               | • Added/customized materials  
• Integrated into infrastructure  
• Narrowed primary audience  
• Added activities  
• Changed order; length of activities  
• Expanded audience  
• Shifted focus to other behaviors  
• Did not complete core elements | Minor adaptation |
| Low fidelity                |                     | Major adaptation or Reinvention |

(Reis et al., 2013)
fidelity/adaptation, calling for more attention of researchers in: a) how to gather evidence of following these guidelines, b) how to make these guidelines a routine part of implementation practice, c) how to determine sources of variance in fidelity, d) changes in the fidelity/adaptation balance across time (i.e. maintaining a better balance at “horizon” that steadily decreases over the length of program implementation), e) making instrumentation to evaluate core components and fidelity more readily available for interventionists, f) how to get program implementers more involved at every stage of program development rather than delivery at implementation time exclusively, and finally, g) increasing the support infrastructure (such as funders and publishers) for more research in this area (Backer, 2001). These recommendations set the stage for specific adaptation considerations, and provided a process of checks and balances for assuring that in adaptation, core elements are remaining and are delineated clearly enough that EBIs can be contextualized with them intact. Several researchers have set out to modify this process; however, in the essence of space, this discussion will further be directed towards state-of-the-science models of adaptation in HIV prevention programming.

Center for Disease Control and Prevention’s MAP Adaptation Guidelines

The Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention (CDC-DHAP) drafted a set of 3-phase guidelines to mapping the adaptation process (MAP). This was articulated in an attempt to provide structure and control to the dissemination of EBIs, specifically targeting those geared towards HIV prevention (McKleroy et al., 2006). The first phase of the MAP guidelines is assessment, ‘assessing’ the new target population’s (the one in which you’d like to adapt an intervention
towards) risk for HIV, identifying the most appropriate existing EBI, and deciding whether or not the agency/institution has the capacity to carry out the identified EBI. The second phase of the MAP guidelines is preparation, ‘preparing’ to implement the EBI in the new target community or with the new target population. And finally, the third phase of the MAP guidelines is implementation, ‘implementing’ and piloting the intervention with the new target population. To assure that each action step is properly addressed and achieved, the MAP guidelines include feedback loops and checkpoints throughout the process, including monitoring, supervision, and evaluation. Though this was one of the first declarations by CDC that the adaptation process, particularly for HIV prevention programs, needed to be standardized—a number of researchers to follow would argue that the process is a bit involved and perhaps unrealistic for agencies that engage in the implementation of HIV prevention programs.

**ADAPT-ITT Model**

Having served as primary investigators for a large number of HIV prevention programs identified as EBIs, Drs. Gina Wingood and Ralph DiClemente devised a systematic approach to adapting programs that is more comprehensive, yet more feasible than the previous MAP program developed by CDC-DHAP. The ADAPT-ITT model informs translation of an EBI for use with a new sample, for a new setting, or using a new implementation format. The model includes 8 sequential steps: 1) assessment; 2) decision; 3) adaptation; 4) production; 5) topical experts; 6) integration; 7) training, and 8) testing (Wingood & DiClemente, 2008). Each of these steps will be described in further detail below:
1) **Assessment** involves conducting focus groups, elicitation interviews, or need assessments to determine the HIV risk profile of the target population being considered. Differences between the original target population for which the intervention was created and tested, and the new target population should be identified during this assessment step of the ADAPT-ITT model. This step additionally entails soliciting information about resources and capacity of the agency to conduct the intervention. The formative data collected at this step should inform the next step, decision.

2) **Decision** involves conducting research on available EBIs and making a decision about which program is most appropriate in achieving the outcome of interest. Furthermore, this step involves deciding whether to adopt or adapt an EBI. If an intervention is presumed to be more efficacious if modifications are made, it is recommended that the intervention is adapted. If not, it is recommended that it would be most efficient to adopt the intervention as is.

3) **Adaptation** involves a pretest methodology that is unique to adaptation research and had not previously been provided in CSAP or CDC’s MAP guidelines and that is, “theater testing”. Theater testing provides an opportunity for members of the target population to come and observe the intervention being carried out. After observing the intervention, these attendees from the target population are asked to complete questionnaires about their receptiveness and the acceptability of the intervention presented. Further, another phase involves members of the target population being invited to “act out” some of the intervention themselves as facilitators. This allows researchers and facilitators (who are not amongst the targeted population) to make observations, and respond to subsequent questionnaires regarding what changes might need to be made to the intervention. The questionnaires include querying
opinions on content, overall language, specific messages, exercises, and the delivery of components of the intervention. Survey responses then serve as “triggers” for open discussion between researchers, key stakeholders, team facilitators, and target population facilitators about what could be enhanced or included in the program, what should be removed, and why.

4) Following adaptation, the production phase involves creating the first draft of the adapted intervention based on recommendations obtained at step 3. Consistent with previous CSAP recommendations, this step emphasizes the need for striking the balance between fidelity (maintenance of core elements) and adaptation. Wingood and DiClemente highlight this step to involve carefully and systematically documenting needed changes, and changes made. The intervention and the modes of component delivery are all open to adaptation, except for core elements that are to remain unchanged.

5) Consulting topical experts involves accepting that sometimes during the adaptation process, there are needs for which researchers lack expertise. This is the step in which researchers should step aside and identify experts in specialty areas outside of their knowledge base.

6) Integration involves utilizing the knowledge gained by consulting topical experts to create a second draft of the intervention. This step additionally entails assuring that intervention materials are written at appropriate reading levels, and that components of the materials remain ‘true’ to the original intervention’s theoretical underpinnings and core elements. This step culminates with creating the third draft of the intervention.
7) The training step involves training all staff involved in intervention implementation. This includes facilitators and co-facilitators, recruitment and retention staff, assessment staff, data managers, and any topical experts that might be needed to teach specific intervention skills.

8) The final step is testing and includes two discrete, sequential steps: a) conducting a pilot trial with approximately 20 participants with the intention of receiving quantitative feedback on the relevance and appropriateness of the intervention to assess “adaptation efficacy”; and b) running a phase 2 clinical trial (using a larger sample size, typically a couple hundred) to evaluate the overall efficacy of the intervention with this population by including a baseline survey, process evaluation measures, and a follow-up at least 3 months after participation in the intervention (Wingood & DiClemente, 2008).

The ADAPT-ITT model is one of the most recent and widely used adaptation process models in HIV prevention intervention implementation. The model is quite comprehensive and includes foundational elements of previous adaptation models such as Roger’s early innovation-decision work, CSAP’s adaptation guidelines, and builds from the CDC’s MAP guidelines on adapting EBIs. There are a number of ways in which the ADAPT-ITT model is especially accessible in HIV prevention work; a few to highlight are a) the involvement of both the community, researchers, facilitators, and key stakeholders throughout the entire process from beginning to end, b) emphasis on planning and documenting throughout the process to maintain fidelity while adapting, and c) creating multiple drafts of the intervention over time to allow for the re-evaluation of what changes are both necessary and acceptable by the target population.
The ADAPT-ITT framework has been utilized in adapting a number of HIV prevention EBIs (Latham et al., 2010; Sullivan, Stephenson, Gratzer, et al., 2014; Sullivan, Stephenson, Grazter, et al., 2014; Wingood, Simpson-Robinson, Braxton, & Raiford, 2011). Having a framework like the ADAPT-ITT model allows for the consideration of testing culturally adapted interventions for efficacy in open trials, and scaling them all the way up through large clinical trials for effectiveness (Barrera Jr, Castro, Strycker, & Toobert, 2013).
CHAPTER 3
METHODOLOGY

The proposed dissertation research involves a two-phase, mixed methods design. Phase 1 involves qualitative data collection, intervention adaptation, expert review of adapted intervention materials, and post-expert review adaptation. Phase 2 involves an open trial of the adapted intervention with quantitative data collection to evaluate target outcomes and process evaluation of the intervention components. Project UPLIFT for this dissertation research are illustrated in Figure 3.1 below:

Figure 3.1 Adaptation/Evaluation Timeline for Current Study
Phase I: Adaptation

Prior to enrolling participants into the first phase of the research, the Project UPLIFT manual was adapted for illness/disease-related content. The intervention was originally designed for persons with epilepsy, and therefore, needed to be adapted for AAWLWHA. Using guidance from an adaptation of Project UPLIFT for cystic fibrosis, the primary researcher made all language in the manual relevant for those living with HIV/AIDS rather than epilepsy replacing words such as “epilepsy” or “seizure disorder” with “HIV” or AIDS”. In addition, given knowledge of stigma regarding mental health in among African American women, language included on the cover and throughout the main intervention manual was changed from “...to treat depression” to “reduce stress and improve mood”. No core elements of the intervention were modified in this pre-enrollment adaptation phase.

The following includes methodology proposed for each phase of this dissertation research. Chapter 4 will include final methodology and findings related to each phase of the research.

*Qualitative Focus Groups*

**Study sample:** Approximately 16 to 18 women living with HIV/AIDS will be recruited from a local AIDS service organization in Georgia, Positive Impact Health Centers, or an organization affiliated or collaborating with Positive Impact. Positive Impact Health Centers is a comprehensive HIV/AIDS care facility that offers HIV primary care, prevention services, HIV testing and counseling, mental health and substance abuse treatment, and housing support. Women will be eligible to participate if they are ≥ 18 years of age, self-identify as Black or African American, have previously
received an HIV or AIDS diagnosis by a healthcare provider, are depressed (mildly or moderately) as defined by a total score ranging from 5 to 14 on the Patient Health Questionnaire-9 (PHQ-9), are cognitively apt, and speak English fluently. Women will be determined ineligible for indicating severe depressive symptoms (a score of 15 or greater on the PHQ-9), suicidal ideation within the past month, or are cognitively impaired such that they are unable to provide informed consent to participate in this research.

**Referrals for Mental Health Concerns:**

Those determined ineligible due to severe depression as determined by the PHQ-9 or suicidal ideation will be referred to the Georgia Crisis and Access Line (GCAL) at 1-800-715-4225. One week after screening participants who are referred to GCAL, the primary researcher (a Masters-level social worker) will call the individual to follow up about their contact with GCAL, assess needs, and provide any resources necessary. Dr. Delia Lang of Emory University, a Georgia licensed psychologist, will serve as clinical supervisor for contact in case of urgent mental health crises or questions regarding safety from the primary researcher.

**Recruitment:** Providers at Positive Impact Health Centers will be informed about the study and asked to refer patients that might be eligible. Several recruitment strategies will be employed. The primary researcher will spend time actively recruiting in the clinic at a regular time that is convenient for clinic staff and patients. Additionally, flyers will be posted in the clinic, at HIV/AIDS related events, and in the community to solicit interest in participation. Online advertisement for participation may also be used.

**Data collection:** Focus groups lasting approximately 60 to 90 minutes will be conducted in-person with approximately 16 to 18 AAWLWHA. There will be a total of 2
to 3 focus groups conducted, each including 8 to 10 women depending on the timing and ease of recruitment. It is hoped that the focus groups will be held at Positive Impact Duluth given that recruitment is planned to take place primarily there, and for the privacy of patients who are accustomed to receiving services at this facility but may not be comfortable meeting at another facility. In addition, for ease of accessibility, a local Atlanta clinic location is also available for use.

Semi-structured focus group guides will be created to include questions regarding psychological distress, coping, social and family support specifically related to HIV/AIDS diagnosis, and the experience of living with HIV/AIDS. This inquiry will help to lead into a discussion of the UPLIFT program for providing coping techniques and potentially combating stress. The primary aim of the focus groups will be to understand the interest in and acceptance of mindfulness-based techniques to cope with psychological distress. In the first focus group, participants will be introduced to the origin and purpose of MBCT, the basis of Project UPLIFT. They will be asked whether they believe that UPLIFT would be useful in improving mood and reducing distress among women in their community, and encouraged to share suggestions on ways to recruit women for participation in the open trial. The primary researcher will also assess interest in mindfulness techniques, and the utility of an intervention such as Project UPLIFT. After receiving formative feedback in these areas, the primary researcher will present content (teachings, relaxation and meditational exercises, poems and quotes) directly from the intervention. The researcher will solicit feedback from focus group participants on the focus, content, and delivery of UPLIFT intervention sessions with special attention to cultural appropriateness. Following the first focus group, subsequent focus groups (a second and possibly third, if necessary) will have a more
narrowed focus, based on prior focus group responses, on the specific content of the intervention, thus allowing participants the opportunity to elaborate on changes that would best suit the specific needs of African American seropositive women. At the end of each focus group, participants will receive $25 for their time. Additionally, the PI will administer a brief questionnaire to collect demographic information for sample descriptive purposes.

Measures for Phase I:

**Screening Measures** will include the following:

**Cognitive Status/Mental Stability** will be assessed by use of the T-MMSE (Telephone-Mini Mental State Examination), (Newkirk et al., 2004) The T-MMSE is an adapted version of the Mini-Mental State Examination and is used to measure cognitive status by asking a battery of questions related to orientation to time and place, attention, naming, repetition, recall, and a three-stage command. This takes approximately 5 to 10 minutes to administer and has been shown to be valid and effective in assessing one’s cognitive state.

**Symptoms of Depression** will be assessed by the Patient Health Questionnaire-9 (PHQ-9), (Kroenke, Spitzer, & Williams, 2001) a 9-item instrument clinicians use to screen for depressive symptoms. Women will be excluded from participation in focus groups if they receive a total score of 15 or greater, indicating moderately severe to severe distress (Kroenke et al., 2001). Referrals will be provided as appropriate.

**Suicidal Intent or Planning** will be assessed utilizing two revised items from the Youth Risk Behavior Survey (Eaton et al., 2012) to query suicidal intent and plans within the past month. The questions will read as follows:

(1) During the past month, did you ever seriously consider attempting suicide?
(2) During the past month, did you make a plan about how you would attempt suicide?

If yes to either of these items, women will be excluded from participating in focus groups and will be referred for mental health services, and the IRB-approved mental health safety protocol described above will be followed.

Data management and analysis: Focus groups with women will be digitally recorded by the PI, transcribed verbatim, and checked for accuracy. Transcripts will be de-identified and all identifying information will be disguised. Once transcribed and checked for accuracy, each focus group transcript will be reviewed by the PI and a second researcher. The data from these interviews will be coded using grounded theory which allows for open coding (identifying concepts or themes), axial coding (matching concepts/themes to subthemes), selective coding (identifying main themes and relating other themes to these), and relational statements (the PI develops hypotheses about how these themes are related), (Crosby, DiClemente, & Salazar, 2011; Strauss & Corbin, 1998). An initial codebook will be created based on focus group transcripts. Codes/themes derived will be compared between the PI and a second researcher to ensure reliability and inter-coder agreement. Where there are discrepancies, the PI and second researcher will meet until a consensus is reached. The PI will code all interviews and transcripts in a similar fashion. Throughout the analysis process, the codebook will be continually modified as necessary.

Coded segments of interviews and focus group transcripts will be reviewed to highlight key codes/themes as well as connections between themes and subthemes. Participant quotations will be compiled and relevant core themes will be developed.
NVivo 11.0, a qualitative data management and analysis software package, will be used (M. B. Miles & Huberman, 1994).

Following the coding of transcripts and identification of themes, the experiences and needs of AAWLWHA will be used to adapt Project UPLIFT. Each intervention session will be examined, including content, procedures, information provided, and exercises used to identify ways that sessions can be made more congruent with the experiences of African American women, and better meet their clinical needs related to HIV management and care.

Post-Focus Group Adaptation

Following analysis of qualitative data collected in Phase 1 of this research, changes will be made to UPLIFT to ensure its’ appropriateness for the African American HIV-seropositive female population. Further, a second researcher involved in qualitative data analysis will review the intervention to assure that major concerns have been addressed, and components that were represented as consistent themes in qualitative data are modified appropriately in the UPLIFT intervention materials. Further, the dissertation committee (Drs. N. Hansen, T. Callands, B. Heckman, and T. Heckman) will review a summary of qualitative findings, the original UPLIFT intervention materials, and the modified UPLIFT intervention materials to determine that necessary modifications have been made and to advise on the adaptation/fidelity balance.

Expert Review

Next, expert review of UPLIFT will be solicited. This expert review will include requesting that four individuals review the most recent adapted version of the intervention prior to Phase II of the study. These individuals will include two
AAWLWHA residing in the state of Georgia; one key informant who either services, educates, or is in close relationship with AAWLWHA in Georgia; and finally, Dr. N. Thompson who developed UPLIFT. The experts will be asked to spend 1 to 2 weeks reviewing intervention materials, noting suggestions for modifications, and spending time advising the primary researcher on suggested changes.

Phase II: Open Trial of UPLIFT

The following describes the final phase of this dissertation research involving open trials of the UPLIFT intervention with a focus on process evaluation for the purpose of determining acceptability and feasibility.

Process and Outcome Evaluation

Study sample: After modifications are made to UPLIFT and the final adapted version of UPLIFT is complete, a total of 20 women (for a desired sample size of about 16 considering attrition) will be recruited from Positive Impact Health Centers and/or collaborating agencies for participation in an open trial. Women will be eligible to participate if they are ≥ 18 years of age, self-identify as Black or African American, have previously received a diagnosis of HIV or AIDS by a healthcare provider, are depressed (mildly or moderately, as defined by a total score ranging from 5 to 14 on the PHQ-9), cognitively apt, and speak English fluently. Women will be determined ineligible for indicating severe depressive symptoms (determined by a score of 15 or greater on the PHQ-9), suicidal ideation within the past month, refusal to be audio-recorded, and/or are cognitively impaired such that they are unable to provide informed consent to participate in this research. Additionally, women who participated in Phase 1 will be presented with specific components of the UPLIFT intervention in focus groups. This
exposure might compromise data on the effectiveness of the intervention in the open trial if these women are allowed to participate. Therefore, women who participate in the focus groups in Phase 1 of this study will be excluded from participation in the Phase 2 open trial groups.

**Referrals for Mental Health Concerns:**

Those determined ineligible due to severe depression as determined by the PHQ-9 or suicidal ideation will be referred to the Georgia Crisis and Access Line (GCAL) at 1-800-715-4225. One week after screening participants who are referred to GCAL, the primary researcher will call the individual to follow up about their contact with GCAL, assess needs, and provide any resources necessary. Dr. Delia Lang of Emory University, a Georgia licensed psychologist, will serve as clinical supervisor for contact in case of urgent mental health crises or questions regarding safety from the primary researcher. Further, mental health concerns that arise during the UPLIFT intervention will be discussed with Dr. Lang to make decisions about how to move forward, and ensure participant safety. All sessions will be recorded and available for review by Dr. Lang should there be a clinical concern.

**Recruitment:** Providers at Positive Impact Health Centers will be informed about the study and asked to refer patients that might be eligible. Several recruitment strategies will be employed. The primary researcher will spend time actively recruiting in the clinic at a time that is convenient for clinic staff and patients. Additionally, flyers will be posted in the clinic, at HIV/AIDS related events, and in the community to solicit interest in participation. Online advertisement may also be used. A total of 20 women will be sought for participation. Although only 16 women are desired for two open trials of UPLIFT, it is expected that approximately four women may not continue through to
the start of UPLIFT sessions due to a loss of interest, schedule conflicts, or lack of availability. Therefore, 20 women will be recruited to account for expected attrition.

**Intervention Implementation/Data Collection:**

Two open trials will be conducted utilizing the adapted UPLIFT trial. These two open trials will be treated as an opportunity for observation before further adaptation, and evaluation of further modifications that might be necessary with the ultimate goal of scaling up to a randomized, controlled trial (Wingood & DiClemente, 2008).

After providing informed consent, women will be asked to participate in 8 UPLIFT sessions by phone, one per week, lasting one hour each. The calls will take place by use of a phone conferencing program such as, ReservationLess Plus where calls can be audio-recorded, monitored by both phone and by a moderator from a computer interface. Participants will be given a specific call-in number and access code to assure the privacy and confidentiality of the call.

UPLIFT sessions will be conducted by use of a scripted facilitator’s manual, and groups will be facilitated by the primary researcher (an African American woman with experience in HIV/AIDS) and a co-facilitator (an African American woman living with HIV/AIDS, or an individual familiar with HIV/AIDS research and trained in UPLIFT). There will be no randomization; women will be openly enrolled into the trial. Two groups will be facilitated including 6 to 8 women in each. When the first group of 8 women is formed, a pre-test assessment will be administered (including the evaluation measures described below). Additionally, women will be asked to provide feedback on each weekly session directly following the session for the day. Additional, process evaluation measures will be administered once the final assessment after UPLIFT has ended. The process evaluation assessments will include acceptability measures, as well
as a client satisfaction measure described in further detail below. When the last UPLIFT group session has been conducted, a post-test assessment will be administered with each participant within a week of last session completion. All assessments will be administered by interviewer over the phone using either the Qualtrics or QDS ACASI programs.

Participants in the UPLIFT open trial groups will be compensated with a $10 gift card for each UPLIFT session attended, and a $15 gift card for the completion of each of the pre- and post-test assessments. Feedback from women in Phase 1 focus groups will be used to decide whether it is best to send women e-cards or mail physical gift cards for participation in the UPLIFT open trials, as well as whether UPLIFT materials should be mailed physically or electronically provided prior to the 1st UPLIFT phone session.

**Screening Measures** will include the following:

- **Cognitive Status/Mental Stability** will be assessed by use of the T-MMSE (Telephone-Mini Mental State Examination). (Newkirk et al., 2004) The T-MMSE is an adapted version of the Mini-Mental State Examination and is used to measure cognitive status by asking a battery of questions related to orientation to time and place, attention, naming, repetition, recall, and a three-stage command. This takes approximately 5 to 10 minutes to administer and has been shown valid and effective in assessing one’s cognitive state.

- **Symptoms of Depression** will be assessed by the Patient Health Questionnaire-9 (PHQ-9), a 9-item instrument clinicians use to screen for depressive symptoms (Kroenke et al., 2001). Women will be excluded from participation in focus groups if they receive a total score of 4 or less (indicating little or no distress), **OR** 15 or greater (indicating moderately severe to severe distress), (Kroenke et al., 2001). This will allow
for the recruitment of women who are minimally to moderately depressed, but not severely depressed. Referrals will be provided as appropriate.

**Suicidal Intent or Planning** within the past month will be assessed utilizing two revised items from the Youth Risk Behavior Survey, (Eaton et al., 2012): (1) During the past month, did you ever seriously consider attempting suicide? (2) During the past month, did you make a plan about how you would attempt suicide?

**Evaluation Measures** will include the following:

In order to assess **acceptability** of the intervention, an 8-item Client Satisfaction Questionnaire will be used. (Attkisson & Zwick, 1982) Formative data on the acceptability of the intervention will be retrieved from the audio recordings of feedback on UPLIFT provided by focus group participants. The recordings will be reviewed by the PI and co-facilitator to make note of necessary modifications to UPLIFT.

In order to assess **feasibility**, attendance records and a 22-item process evaluation measure will be used. This measure has been used with PWE samples in evaluating the efficacy of Project UPLIFT, (Walker et al., 2010)

In order to assess **preliminary efficacy** of the intervention, changes in stress, PTSD, anxiety, and depression for which measures will be described in detail below. Additionally, changes in knowledge and skills will be compared from pre-test to post-test.

**Knowledge and Skills** will be assessed using a measure used with samples of PWE in previous evaluations of Project UPLIFT (Thompson et al., 2010). The knowledge items include true-false response options. The skills items include Likert-scale response options that query both the value and frequency of the skill learned and utilized.
Mindful attention and awareness will be assessed by utilizing the MAAS, a 15-item measure designed to evaluate one’s openness, receptiveness, and awareness to attending to the present- core characteristics of mindfulness ($\alpha=0.80-0.87$) (K. W. Brown & Ryan, 2003; MacKillop & Anderson, 2007).

Depressive Symptoms will be assessed by utilizing a modified version of the Beck Depression Inventory ($\alpha=0.88$), (mBDI), (Beck & Steer, 1984; Beck et al., 1996; Dori & Overholser, 2000). This measure includes 21 original BDI items as well as scaled responses ranging from 0 (positive) to 4 (severe). During screening, patients will be enrolled if they indicate mild depression, yet excluded if severely depressed. Therefore, symptoms of depression could be potentially low. The modified version of the BDI is most appropriate because of its’ ability to detect subtle differences in depression (Dori & Overholser, 2000).

Anxiety Symptoms will be assessed by utilizing the Beck Anxiety Inventory (BAI), ($\alpha=0.92$) (Beck et al., 1988), a 21-item measure of anxiety experienced in the past week. The measure includes response choices that range from 0 (Not at all) to 4 (Severe).

Stress Symptoms will be assessed by utilizing the Perceived Stress Scale (PSS-10; $\alpha=0.84$) (Cohen, 1988), a 10-item measure assessing the “perception” of stress experiences in the past month. The measure includes response choices that range from 0 (Never) to 4 (Very Often).

Symptoms of Post-traumatic Stress Disorder (PTSD) will be assessed by utilizing the PTSD-8 ($\alpha=0.84$) (Hansen et al., 2010). The measure contains 8 items, consisting of 4 Intrusive items, 2 Avoidance items, and 2 Hypervigilance items. It includes Likert-scale response options that range from 1 (not at all) to 4 (all the time).
**Coping** will be assessed by utilizing The Brief Cope (α=0.74-0.89) (Carver, 1997), a 28-item measure of how one deals with difficult/stressful situations or life events across a broad range of strategies. The measure includes response choices that range from 1 (I haven’t been doing this at all) to 4 (I’ve been doing this a lot).

**Coping Self-Efficacy** will be assessed by utilizing The Coping Self-Efficacy Scale (CSES), (α=0.95) (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006). The measure is a 26-item assessment of perceived self-efficacy for coping, particularly with challenges and threats that arise. Items present scenarios such as “when things aren’t going well for you, or when you’re having problems”, how confident one feels for example to, “talk positively to yourself”. The measure includes response choices that range from 0 (cannot do at all) to 10 (certain can do). The measure has been used with many HIV-infected samples (Rodkjaer et al., 2014).

**HIV Shame** will be assessed by utilizing the HIV and Abuse Related Shame Inventory (HARSI) (α=0.93) (Neufeld et al., 2012). The measure has 31 items and evaluates whether a person experiences feelings of shame as it relates to being HIV-positive and/or being sexually abused. The measure includes response choices that range from 0 (Not at all) to 4 (Very much).

**HIV Treatment Utilization** will be assessed by utilizing a measure from prior studies evaluating treatment utilization and medication adherence. The measure asks about primary care and specialist visits attended in the past 4 months, as well as medications prescribed (Meade, Hansen, Kochman, & Sikkema, 2009).

**Data management and analysis:** The purpose of the evaluation portion of this proposal is to collect acceptability and feasibility data to identify potential hurdles in the delivery of Project UPLIFT, and to evaluate its’ preliminary efficacy. Formative
evaluation data will provide information about how to culturally contextualize the intervention for this group attending to both surface and deep structure of intervention components and delivery (Resnicow et al., 1999). Process evaluation data will be obtained from attendance records from each Project UPLIFT intervention session, treatment fidelity (how closely the PI followed the manualized program protocol as assessed by review of audio-recordings and supervision by a clinical psychologist) as well as a formal measure, and acceptability of Project UPLIFT as measured by the CSQ-8. Pre- and post- data will be utilized to assess the preliminary efficacy of Project UPLIFT for this sample. This data will include changes in knowledge, skills, and symptoms of stress, depression, anxiety, and PTSD.

Data analysis will include inspection for basic assumptions of normality, variability, and missing-ness to determine if data transformations or the use of non-parametric techniques are needed. Dropouts and completers will also be compared on baseline characteristics to assess whether missing data is missing at random.

Changes on constructs of stress, anxiety, and depression will be observed. Further, due to the small size of the sample, effect sizes will be evaluated to determine overall magnitude of effect of the intervention for this sample (Becker, 2000). Additionally, clinical significance of the intervention will be assessed by observing how much individual participants changed on constructs of stress, anxiety, and depression from pre-to post-test assessment. The criteria used will focus on behavioral measures and the percentage of participants who may have moved from dysfunctional to functional based on cut-off criteria for each of these measures (Jacobson & Truax, 1991) Further, the percentage of changes and non-changes for the sample, distinguished by completers and non-completers will be described. This will inform the potential and
importance of scaling up to a full randomized, controlled trial with a much larger sample size.
CHAPTER 4

ADAPTING AND EVALUATING A TELE-DELIVERED, MINDFULNESS-BASED COGNITIVE THERAPY INTERVENTION FOR AFRICAN AMERICAN CISGENDER AND TRANSGENDER WOMEN LIVING WITH HIV/AIDS IN GEORGIA

Abstract

Literature suggests that seropositive African American women are at elevated risk for depressive symptoms compared to their seropositive counterparts. Depressive symptoms have been linked to a number of HIV/AIDS-related health predictors and outcomes including medication and care adherence, quality of life, and overall survival. Project UPLIFT, a mindfulness-based cognitive therapy intervention originally designed for persons with epilepsy (PWE) involves 8 weekly telephone-based group sessions, and has been shown effective in reducing depressive and anxiety symptoms among PWE. Focus groups were used to assess the appropriateness and acceptability of Project UPLIFT for HIV seropositive African American women. To assure available mental and behavioral health support, seed recruitment took place at a specific AIDS-service organization (ASO) in Georgia. Recruitment thereafter included clinic flyering and word-of-mouth. Focus groups took place at an ASO location convenient to most participants, and lasted between 1.5 and 2 hours. Initial focus groups with seropositive transgender and cisgender African American women revealed that while well received, necessary modifications might include reducing the reading level of Project UPLIFT content and altering particular mindfulness-based exercises to make them more relevant and acceptable for this population. Project UPLIFT could be a promising avenue for improving the mental health of HIV seropositive African American women. Next steps include having intervention materials reviewed by persons who work with this population in both clinical and non-clinical settings, and piloting the modified version of the intervention with a sample of the target population.
Introduction

According to the Centers for Disease Control and Prevention (CDC), Georgia ranks fifth in the country for new HIV diagnoses. In 2015, CDC reported that of all racial/ethnic groups, African American women disproportionately represented approximately 64% of all new HIV infections among women in the United States.

A recent study found a significant association of low CD4 count and poor ART adherence with untreated depression, where 58% of the sample of African Americans living with HIV/AIDS exhibited elevated depressive symptoms (CES-D >16), (Amanor-Boadu et al., 2016). Approximately 20% to 40% of PLWA (PLWHA) experience depression, as compared to 6% to 10% of the general population, (National Institute of Mental Health (U.S.)) In populations of PLWA, depressive symptoms are related to stigma, social support, stress, trauma, HIV diagnosis as a traumatic stressor, shame, coping strategies, sexual abuse (both in childhood and adulthood), and anxiety (Bennett, Traub, et al., 2015; Chaudoir et al., 2012; Earnshaw, Smith, et al., 2013; Kalichman et al., 2000; Persons et al., 2010; Simoni & Ng, 2000; Vyavaharkar et al., 2007). Additionally, in some samples of PLWA, African American women experienced greater depression than other HIV-seropositive subpopulations (Moneyham et al., 2000). There is also evidence that African American women living with HIV often do not receive appropriate or adequate depression treatment compared to other women living with HIV/AIDS (Cook et al., 2014; M. S. Miles et al., 2007; Moneyham et al., 2000).

There are no known interventions that explicitly address depression among AAWLWA. Only one known behavioral intervention currently exists specifically targeting AAWLWA, and has been deemed a high impact prevention program by the
CDC. WILLOW, a program adapted from SISTA, is a social-skills building and educational intervention targeting heterosexual African American women who are HIV-positive (Fuller et al., 2007; Wingood et al., 2004). The intervention consists of four 4-hour sessions facilitated by two female facilitators and held in a community-based setting. The intervention focuses on increasing knowledge about STIs and HIV, communication skills, how to discern between healthy and abusive relationships, and teaches coping skills, condom use and negotiation skills, and how to establish and maintain support networks, while emphasizing gender pride. The intervention was evaluated for efficacy in an RCT of 366 African American seropositive women in Georgia and Alabama. Over 12 months, women in the intervention group reported fewer episodes of unprotected vaginal intercourse, an increase in the frequency of condom use during intercourse, a lower incidence of Chlamydia and Gonorrhea infections, greater HIV knowledge and condom use self-efficacy, more network members, fewer beliefs that condoms interfere with sex, and fewer partner-related barriers to condom use, as well as demonstrated greater skill in using condoms than those in the comparison control group (Wingood et al., 2004).

Despite WILLOW focusing on behavioral health concerns and the success of WILLOW in an efficacy trial, it is clear that more public health efforts should be devoted to directly exploring mental health namely depression (along with other psychosocial issues) among HIV seropositive African American women. It is hopeful that WIHS (Women’s Interagency HIV Study), encompassing the largest cohort of HIV-infected women with specific sites in the Southern region of the U.S., will help to inform needed interventions for this population (Barkan et al., 1998). There is a need for the development of new interventions that aim to reduce depressive symptoms and/or the
adaptation of currently available evidence-based interventions (EBIs) used with other populations to be contextualized for use with AAWLWHA.

Adaptation is defined as “the degree to which an innovation is changed or modified by a user in the process of its adoption and implementation” (Rogers, 1995). Though scarce, in the 20 years following Rogers’ work, there have been several frameworks established to provide guidance in the adaptation of behavioral interventions, as well as redefining the essence of adaptation by both definition and process. In the realm of HIV research, literature often justifies the establishment of these guidelines as primarily an effort to provide consistency in making decisions about the approach to adaptation of evidence-based programs. Evidence-based programs or EBIs are those declared by Center for Disease Control and Prevention’ (CDC) as best practice interventions (McKleroy et al., 2006). EBIs are identified as effective typically through the process of clinical trial evaluation.

There are a number of frameworks that have been utilized to adapt behavioral interventions to include Rogers’ innovation-diffusion model, Center for Substance and Abuse Prevention’s (CSAP) Adaptation Model, Center for Disease Control and Prevention’s (CDC) MAP guidelines, and the ADAPT-ITT model (Backer, 2001; McKleroy et al., 2006; Rogers, 1995; Rogers Everett, 1995; Wingood & DiClemente, 2008). While these adaptation models can be useful in informing interventions focused on the improvement of mental health for AAWLWHA, they often require a wealth of time and finances.

A recent review of adaptation frameworks concluded that although there is lack of overall consensus in best strategies for adaptation given the unique considerations of each research project, there are some commonalities across all of these frameworks.
The adaptation described in this paper followed this general five-step framework for cultural adaptation of Project UPLIFT, an MBCT intervention: information gathering, preliminary design, preliminary testing, refinement, and final trial (Barrera Jr et al., 2013). This framework required a more practical approach to adapting Project UPLIFT for AAWLWHA in Georgia as dissertation research.

Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) is a mindfulness-based cognitive therapy (MBCT) intervention that has shown efficacy in reductions of stress, anxiety, and depressive symptoms in people with epilepsy and those with cystic fibrosis (Thompson et al., 2015; Thompson et al., 2010; Walker et al., 2010). The intervention is evidence-based and cost-effective, delivered over 8 weekly sessions, and has been administered remotely by telephone or the web. Due to the success of other MBSR and MBCT interventions used with other HIV-seropositive populations (Carlson, 2012; Creswell et al., 2009; Gonzalez-Garcia, Ferrer, Borras, Munoz-Moreno, et al., 2013; Jam et al., 2010; Moskowitz et al., 2015; Riley & Kalichman, 2015; Robinson et al., 2003; SeyedAlinaghi et al., 2012; Yang et al., 2015), and the ease of Project UPLIFT being adapted for other chronic disease populations (Thompson et al., 2015), the adaptation and evaluation described in this paper will address an important problem by applying evidence-based methods and technologies via tele-therapy intervention delivery for the treatment of depression among AAWLWHA.

Despite various adaptation frameworks that inform the current research, there is consensus among these models regarding steps that are shared across frameworks. Utilizing Barrera’s consensus model for cultural adaptation, the following steps were taken in the adaptation of UPLIFT for AAWLWHA in Georgia:
Evaluation of adapted interventions is a critical step in assessing whether an EBI has been successfully modified to meet the needs of the target population. Formative evaluation data will provide information about how to culturally contextualize the intervention for this group attending to both surface and deep structure of intervention components and delivery. (Resnicow et al., 1999).

**Preliminary Steps- Assessment**

In consideration of evaluating the UPLIFT intervention for AAWLWHA, it was critical to review the literature on mindfulness-based interventions to establish the potential utility of the intervention with this group. Additionally, it was important to discuss adaptation with the primary creator of the UPLIFT intervention to explore opinions on whether the intervention was adaptable for the target population. Finally, experts in working in the areas of both HIV/AIDS-related mental health interventions and in tele-delivered interventions for PLWHA were consulted to introduce UPLIFT. All agreed that UPLIFT had potential promise for AAWLWHA, and that assessing
acceptability and feasibility of the intervention for this target group was an important step and addition to the scientific literature base.

**Adaptation and Formative Evaluation**

*Step 1: Translation and Preliminary Adaptation of UPLIFT Materials*

Figure 4.2 displays the intervention session titles of UPLIFT; these sessions represent the content of the intervention of its original design. The first step in adapting UPLIFT for African American women with HIV/AIDS included making changes to disease-specific information in the intervention materials. Further, any real-life examples of experiences were included and made relevant to living as a woman with HIV or AIDS. In order to assess the accuracy of making these changes, the developer of the EBI as well as another research team member was asked to review the materials to ascertain whether all appropriate changes had been made. This became the first adapted draft of UPLIFT for persons living with HIV or AIDS, and specifically, for AAWLWHA. This draft was then utilized for formative evaluation of the modified intervention with members of the target population.

<table>
<thead>
<tr>
<th>MBCT Sessions</th>
<th>UPLIFT Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Automatic Pilot</td>
<td>1. Monitoring Thoughts*</td>
</tr>
<tr>
<td>2. Dealing with Barriers</td>
<td>2. Challenging and Changing Thoughts*</td>
</tr>
<tr>
<td>3. Mindfulness of the Breath</td>
<td>3. Coping and Relaxing</td>
</tr>
<tr>
<td>4. Staying Present</td>
<td>4. Attention and Mindfulness</td>
</tr>
<tr>
<td>5. Allowing/Letting Be</td>
<td>5. The Present as a Calm Place</td>
</tr>
<tr>
<td>6. Thoughts are not Facts</td>
<td>6. Thoughts as Changeable and Impermanent</td>
</tr>
<tr>
<td>7. How can I best take care of myself?</td>
<td>7. Pleasure and Reinforcement*</td>
</tr>
<tr>
<td>8. Using what has been learned in the future</td>
<td>8. Relapse Action Plans</td>
</tr>
</tbody>
</table>

*Figure 4.2 MBCT Sessions Translated to UPLIFT Sessions*
Step 2: Formative Evaluation of Modified UPLIFT Intervention

Methods

Focus groups were planned to formatively evaluate the acceptability of Project UPLIFT for women living with HIV or AIDS in Georgia, to contextualize plans for further adaptation, as well as to elicit direct feedback on the UPLIFT intervention materials and facilitation. Once approval from the university Institutional Review Board was obtained, women were recruited from an AIDS-service organization (ASO) that provides care to the local Atlanta, Georgia and surrounding areas. Flyers were posted throughout the agency and staff that provided a variety of services to the target population were briefed on the purpose of the study, as well as eligibility criteria. Women were asked to contact the number indicated on the flyer to be screened by phone. It was expected that recruitment would reach beyond this ASO. However, given the nature of the project (recruiting women who were living with HIV/AIDS and comorbid depression), it was expected that for mental health safety, it would be more comfortable for women to have the option of reaching back to agency personnel if not comfortable communicating with study staff about psychosocial concerns.

In order to be eligible for focus group participation, women had to be 18 years of age or older, identify as Black or African American, identify as a woman, have previously received an HIV or AIDS diagnosis by a healthcare provider, be mild to moderately depressed (as defined by a total score ranging from 5 to 14 on the PHQ-9 as a screening measure), cognitively apt, and speak English fluently. Women were determined ineligible for indicating zero to little OR severe depressive symptoms (a score of 0 to 4, or 15 or greater on the PHQ-9), suicidal ideation within the past month, or cognitively
impaired such that they are unable to provide informed consent to participate in this research.

Screening measures were as follows:

Cognitive status/mental stability was assessed by use of the T-MMSE (Telephone-Mini Mental State Examination), (Newkirk et al., 2004). The T-MMSE is an adapted version of the Mini-Mental State Examination and is used to measure cognitive status by asking a battery of questions related to orientation to time and place, attention, naming, repetition, recall, and a three-stage command. This takes approximately 5 to 10 minutes to administer and has been shown to be valid and effective in assessing one’s cognitive state.

Symptoms of depression were assessed by the Patient Health Questionnaire-9 (PHQ-9), (Kroenke et al., 2001), a 9-item instrument clinicians use to screen for depressive symptoms. Women were excluded from participation in focus groups if they received a total score of less than 5 indicating little no distress, OR 15 or greater, indicating moderately severe to severe distress (Kroenke et al., 2001). Referrals were provided as appropriate.

Suicidal intent or planning was assessed utilizing two revised items from the Youth Risk Behavior Survey (Eaton et al., 2012) to query suicidal intent and plans within the past month. The questions were as follows:

(1) During the past month, did you ever seriously consider attempting suicide?

(2) During the past month, did you make a plan about how you would attempt suicide?
If yes to either of these items, women were excluded from participating in focus groups, and referrals were provided as appropriate. The principal investigator (PI) of the current study is a trained Masters-level social worker. Additionally, a Georgia-licensed clinical psychologist oversaw the mental health aspect of the project to be consulted whenever the PI had concerns about women who were particularly distressed, or if there were concerns about imminent danger to self or someone else.

A total of three focus groups were conducted at a local ASO, and lasted approximately 2 hours. Focus groups were conducted by 2 African American women trained in the UPLIFT intervention, as well as a graduate research assistant who assisted with check-in and facilitation of the groups. The groups were facilitated by use of a structured interview guide, and the guide was iteratively adapted from one focus group to the next. To ensure safety and oversight in the case of mental health concerns, an agency staff person was present in the facility at all times while focus groups were being held privately in a designated room. Women were provided $25 cash for participating in focus groups.

Analysis

All focus groups were audio-recorded, and later transcribed verbatim by study staff. The PI listened to audio recordings and checked transcripts for accuracy. An initial codebook was developed based on a priori codes determined to assess acceptability and suggestions/changes desired for UPLIFT material revision. As new themes emerged, they were added to the codebook.

To assist with data management and analysis, transcripts were uploaded into qualitative analysis software, NVivo 11. The PI of the study coded the transcripts developing and refining the initial codebook established. A second coder, a graduate
research assistant working on the study, also analyzed the transcripts to identify codes. The two coders discussed codes/themes to identify any potential discrepancies. This discussion continued until a consensus was met about the codes/themes that should remain. No major discrepancies were identified.

**Results**

A total of 36 women (24 cisgender and 12 transgender) were screened for participation in focus groups. Among women who did not qualify for the study (n=10), two women had scores too high (15 or greater) on the PHQ-9, seven women had scores too low on the PHQ-9 (ranging from 0 to 4), and one woman was deemed ineligible due to responding “yes” on an item regarding suicidal intent. The IRB-approved mental health safety protocol was followed.

Of the women, who did qualify for focus group participation (n=26), a total of 18 women (12 cisgender; 6 transgender; see Table 1 for demographics) participated in three focus groups. All participants (n=18) identified as a woman, and as African American. On average, the women were about 49 years of age (range: 30-65); more than 88% of the women were over the age of 40. Half of the sample had obtained at least a high school diploma/GED, and another almost 40% had completed some college. All of the women had incomes of approximately 25K annually or less. Most (n=11) reported their relationship status as “Single, Never Married”. The majority of the women that participated in the focus groups had been diagnosed with HIV/AIDS at least 15 years prior, and another 40% reported being diagnosed 20 or more years prior. Based on the PHQ-9 (see Table 2), women had a mean score of 9.24 (SD=3.05), indicating moderate distress based on self-reported depressive symptomology.
The focus groups were held at multiple locations of the ASO in which primary recruitment took place between January and March of 2017. After observing some differences between self-reported psychosocial experiences via screening and having an influx of unexpected interest in the study from transgender women, the PI decided to conduct one focus group with solely transgender women, one with solely cisgender women, and a final group including both cisgender and transgender women combined.

Acceptability

Overall, women expressed acceptability of the UPLIFT intervention. During focus groups, some women shared how they had previously been introduced to similar exercises, that they “already practice something like this”, or could see how this might help “in my everyday life”. Table 3 includes the codes/themes related to acceptability of UPLIFT, and suggestions/changes desired for implementation of the intervention with women in their target group. Decisions related to modification/adaptation to the intervention are also displayed in the table. Participants shared that they believed UPLIFT would be very helpful to them, but also for other women like them living with HIV or AIDS. There was a desire to assure that helpful programs existed for the younger generation of women living with HIV/AIDS, a group referred to by transgender women as their “daughters” or “young sistas”.

During the focus groups, participants were asked to give specific feedback on individual portions of the intervention. After each teaching component and relaxation or mindfulness-based exercise, feedback was generally favorable with women sharing that they “really like this”. Though there were a couple specific areas in which participants indicated they desired changes to the material (will be discussed in further detail below), they all evaluated the overall intervention favorably. Feedback of the overall program
was solicited at the end of the focus groups as a concluding check-in, and most shared that they thought that it was “really good”. No one gave unfavorable feedback of the program. One woman said, “I really like this, I hope ya’ll call me to be in the real groups when they start.” Others agreed and seemed to share the same sentiments. In concluding another group, when asked if the UPLIFT program was something the women would want to actually participate in, the group responded in an overwhelming chatter of “Mmhmm. Yes. Absolutely.”

As it relates to specific UPLIFT content most accepted, women seemed to especially enjoy the poems and quotes throughout the intervention sessions. They found them to be highly relatable and analogous to their life experiences. When done presenting most of the poems and quotes in the program, there was often unsolicited feedback such as, “I like that it was just... It made me think. Yeah it did. It made me think.” or “That’s cute. I like it.” In response to UPLIFT’s closing poem entitled *Wild Geese*, one woman responded, “It makes me think about how I don’t have to beat myself up about my past.”

Changes Desired

Though few, participants expressed that there were a few changes they would appreciate to specific exercises in the UPLIFT program. During Sessions 1 and 2 of the intervention (which includes foundational educational material on depression, mindfulness, and cognitive-behavioral techniques, some participants provided feedback that the material was difficult to ingest. One woman stated, “This reminds me of NA [Narcotics Anonymous]...It’s books, books, books, books, and I got some books that I’ve never read before that I bought. And I was like ooh...this is a bit much.” Other women
agreed that perhaps the text was a bit heavy and difficult to understand. In comparison, it seemed that women preferred interactive exercises more than the reading/teaching components, but understood that these were necessary.

When reviewing the Body Scan, a relaxation exercise, some women mentioned that they would prefer the exercise to be less lengthy and detailed. They expressed that the scan might not hold everyone’s attention the entire time, saying, “Everything needs to be put together a little bit... more... It's too spread out.”, and “I’m going to share that these kinds of exercises might be difficult for some to focus on.” Others believed that the exercise was useful including responses like, “I feel great.” and I feel “stress-free.” at the culmination of the exercise. Overall, the three-minute breathing scan was more easily accepted as participants felt that it was more “direct”, and quicker to do. It seemed that participants were comparing the full body scan to the 3-minute breathing space.

When reviewing the Pebble Exercise, a mindfulness-based exercise, some participants had an adverse reaction to the pebble being placed on their desks in preparation for the exercise. When the facilitator inquired about the reaction, a participant shared that the pebble reminded her of her drug addiction, “I'm a recovering addict... And that’s what I gave up [crack]. Reminded me of that. It really did. I couldn't focus on what you was saying cause my mind was like.. what is this?” Another participant agreed that she had a similar reaction to the pebble while another shared that she was a bit further along in recovery, and that the pebble was not bothersome for her but that she could understand it being bothersome for someone in a different place [in recovery].

In addition to soliciting feedback on specific UPLIFT content and exercises, participants were asked to give recommendations on a number of UPLIFT
administration and facilitation-related considerations. Women were asked their opinion about best strategies for recruiting women to participate in the full UPLIFT program (open trials in Phase 2 of the current research), and most responded that flyers should go up in clinics “just like for these [focus] groups”. Additionally, women shared that they learned about focus group recruitment because flyers were shared on an online social media page where members were all African American women living with HIV or AIDS; a photo of the flyer was shared by a member of the group who had seen the flyer in the clinic. Other recruitment recommendations were to provide flyers to health educators in the clinic who were well connected to women; one health educator was mentioned in multiple focus groups, particularly by transgender women. The women shared that she was well connected, and that, she could assist with recruiting women for open trials.

**Step 3: Adapting UPLIFT-Version 2**

Based on analysis of qualitative data from focus groups conducted with cisgender and transgender women- the intervention materials were modified in the ways indicated in Table 3. In summary, the overall reading level of the intervention was decreased, the teaching content was modified to be more direct, the pebble exercise was modified to include a shell instead, and music was included in the Seeing and Hearing Exercise. These modifications were used to develop the second version of the UPLIFT intervention. This version of the intervention materials was used to provide to experts for full review on the intervention materials, and to solicit feedback on ways to improve the intervention based on their expertise and perspectives.
Methods

Step 4: Expert Review/Feedback

Expert feedback on the second version of UPLIFT was solicited to obtain another perspective of best practice, acceptability, and feasibility of the intervention for AAWLWHA.

Four experts were invited to conduct a thorough review of the intervention materials. These experts served the following roles: 1) a cisgender African American woman living with HIV; 2) a transgender African American woman living with HIV; 3) a health educator with over 20 years of experience working in HIV communities of color; and 4) the licensed clinical psychologist involved in the development of the UPLIFT intervention. These experts were provided UPLIFT materials and asked to spend approximately 2 weeks looking over the intervention manuals (both the facilitator and participant versions) in thorough detail, to note any what they liked, disliked, any changes they would suggest; and to provide that feedback to the principal investigator. Additionally, experts were asked to share their overall thoughts about the UPLIFT materials and the program’s appropriateness for the target population. The principal investigator requested that feedback was provided during a scheduled in-person informal interview. One key expert was unavailable for an in-person interview and had very limited feedback, which was shared via e-mail. Experts were provided $40 as compensation for their time.

Results

For the purposes of protecting the identities of the individuals who participated in the expert review and feedback component of this study, no demographic characteristics will be shared. All IRB guidelines were followed in the recruitment, and
consenting of experts. However, the description of feedback provided will be completely blinded.

Overall, all four experts believed that the intervention seemed appropriate for its target population, AAWLWHA. There were a few specific areas where suggestions were given for potentially modifying the materials, and those suggestions will be discussed below. There were no areas or content that either of the experts believed should be removed, or that would be inappropriate or unacceptable to this target group of women.

*Teaching content in UPLIFT.* Consistent with what was shared in focus groups with women-about the first version of UPLIFT, one expert shared that some of the information in the intervention manuals was a bit “complex” and needed to be more “straight to the point”. Specific slides were identified where the language needed to be changed. One example included less mentions of “mindfulness-based cognitive therapy” to “including both the practice of mindfulness and cognitive behavioral therapy”, then further explaining the purpose of both. In discussing this feedback, it was decided that lowering the reading level further would help to make the lessons and exercises a little clearer to the women.

*Relatability.* One expert inquired as to whether facilitators of the intervention would be HIV-positive or not. It was explained that in previous facilitation of UPLIFT for persons with epilepsy, the co-facilitator has also had epilepsy. Due to limited resources, this dissertation study may not be able to include an African American woman living with HIV/AIDS; however, if found to be acceptable and feasible- a future randomized, controlled trial would include the training of an African American woman living with HIV or AIDS to co-facilitate UPLIFT along with someone who is fully trained to lead UPLIFT program sessions. In the meantime, the expert suggested that in
demeanor, the facilitators always approached facilitation of the groups as if they were themselves living with HIV/AIDS. She expressed that this would make a difference in the receptiveness of information shared during sessions. Further, the overall theme of her suggestions echoed the sentiments of not making women feel more stigmatized or that they were living with some big “thing” that the program was dealing with. Ultimately, she believed that this could be achieved via relatability by a huge effort on the part of the facilitators.

*Specific Language.* During in-person feedback, one of the experts emphasized the importance of encouraging women to explicitly “stop” before beginning specific relaxation exercises. This advice was shared in the context of all the responsibilities and “worries” women had, and that it was nice to have a space to practice being mindful, but that perhaps women in the target population needed an additional opportunity to “actually tell themselves aloud to STOP”, before embarking on some of the exercises taught. The expert believed that this would have relevance if and when women were out practicing these skills on their own beyond participation in UPLIFT.

*Shell Exercise.* One expert shared her potential reservations about using a shell as the object to focus on for the particular mindfulness exercise where the pebble was replaced. Initially, given what was shared in focus groups, she agreed that this might be a better option, but also presented ways in which the shell might be unacceptable for some women if swimming had a negative connotation for them. It was decided that using the shell might be the next best option, but to closely evaluate whether women found the use of this object was acceptable, or whether they suggested using a different object. Opportunities to do so will be discussed later in this paper.
Step 5: Adapting UPLIFT: Version 3

Based on feedback from expert review, the intervention materials were modified further. These modifications were integrated into the third version of the intervention UPLIFT for AAWLWHHA. The third version of intervention materials were planned for the second phase of the project, open trials of the intervention that will be discussed further in a separate paper.

Discussion

In assessing the acceptability of UPLIFT formatively with women and through expert review, the intervention was found to be both acceptable, culturally appropriate, and was viewed favorably overall.

Aside from the pointed questions that were asked during focus groups, several lessons were learned that will inform future research on UPLIFT for this specific target group. Firstly, some women who qualified to participate in focus groups had difficulty attending. The main barriers noted included transportation and accessibility. Though the focus groups were held at two ASO locations where seed recruitment took place (meaning that many women were receiving care at the facilities for which focus groups were held), women were did not have personal transportation, had difficulty getting someone to bring them, or had difficulty accessing public transportation and traveling to the facility location. One facility was a bit far from the nearest bus station which meant a long commute and potentially a long walk from the last station to the facility. The primary researcher received several calls prior to focus groups of women who had difficulty making it. This further supports the usefulness of UPLIFT in telephone format as will be discussed later. Secondly, prior to the UPLIFT focus groups, the researchers had not considered other limitations that might make it difficult to participate in the
focus groups. One woman who attended groups had marked visual impairment which made it difficult for her to enter the building and navigate to the group room. This prompted the inclusion of a related question on the screening form to assure that women who were eligible and participated did not have either hearing or vision impairment that prevented them from accessing intervention materials or listening to the intervention sessions.

In focus groups, women shared that they believed the intervention would be helpful in relaxing, and in coping with everyday stressors they often experienced. Women talked about being overwhelmed, and needing to find spaces to be more mindful. Further, a couple women discussed how they were hot-tempered and easily triggered by conflict; in those moments, women believed that the skills gained, particularly mindfulness and relaxation exercises, might help them to settle and not act out aggressively. Of all the content presented, women seemed to especially favor the poems and quotes. This is not surprising as previous mindfulness training programs have found that participants enjoy relating by way of allegorical examples. Additionally, women found the 3-minute body scan to be easily accessible and reported it highly likely that they would use it again. Some women mentioned having already been exposed to the 3-minute body scan (or something like it by way of their physician or from another care provider. Further, when discussing 3–minute body scan, it seems as if women favored it over the full body scan because it appears to be a shorter, more straightforward way of relaxation by scanning the body. This is also not surprising as previous studies, including a pilot trial of UPLIFT for persons living with epilepsy where one participant expressed the potential guilt she might feel taking the time to complete an exercise like the body scan (Walker et al., 2010).
Despite favorable feedback on UPLIFT, there were two specific exercises that raised concerns for a couple of the focus group participants. Firstly, the body scan seemed to be too detailed and lengthy, and not “direct” enough. However, most of the women participating saw great use in the exercise and felt a lot more relaxed when it was done. Secondly, the “pebble” exercise raised concerns for women who were recently recovered from crack cocaine. Given that many AAWLWHAs are infected by intravenous drug use and many have substance use histories (CDC), this is a critical concern for the principal investigator of this study. Further, the women enrolled in the study who were comorbidly depressed and living with HIV/AIDS discussed their substance use histories throughout the group, demonstrating the need for further exploration of these relationships. Depending on the success of open trials, it is possible that substance use is something more directly addressed in future versions of UPLIFT, and potentially other behavioral interventions with similar outcome goals.

In addition to sharing feedback on UPLIFT content and exercises, participants were asked to give feedback on the format of the intervention after being reminded of why and how UPLIFT was more easily accessible in phone format for persons living with epilepsy (Thompson et al., 2010). While one women seemed to prefer in-person interaction, others saw the value of privacy and accessibility via phone groups. This format seemed to be acceptable for most women after discussing how transportation and the risk of confidentiality regarding status were considered as barriers to in-person participation. Other women believed this to be a similar format as “prayer line groups” they’d previously participated in. Given the relevance of spirituality for African American women with HIV/AIDS and correlates of spirituality/religion to depression for AAWLWHAs (Braxton et al., 2007; Dalmida, 2006; Dalmida, Holstad, Diiorio, &
Laderman, 2009; Dalmida et al., 2011), this was an important contextual finding. This focus group feedback regarding format of UPLIFT demonstrates acceptability of this telephone format. However, given that some women had initial concerns, process data during open trials will query the phone delivery format. Though UPLIFT has never been conducted in an in-person format, this might be a future consideration if presented, though it would require adaptation and formative evaluation independently.

**Limitations**

As with any qualitative research, these findings are not generalizable. The sample was limited to African American women with a diagnosis of HIV or AIDS, and living in the state of Georgia. Further, most women initially recruited for focus groups learned of the study by way of a connection to the ASO in Atlanta or surrounding area. Therefore, the formative feedback provided by women participating in the focus groups is only a narrow perspective on acceptability. It is possible that women from other geographic areas might have more diverse experiences related to coping with stress, anxiety, and depression, and different views on the appropriateness of UPLIFT.

Focus groups have been known to be one of the most effective ways to obtain formative feedback on behavioral interventions; however, they are not without fault. It is ideal that women would be exposed to every component of the intervention during focus groups. However, given time limitations and as not to burden participants, focus groups were limited to approximately 2 hours each. This did not allow coverage of the 8-week intervention in its entirety though facilitators covered a core element from each individual session during each focus group.

Additionally, with greater financial and staff resources, it is possible that the perspectives shared in response to UPLIFT could have been enriched by facilitating
focus groups with more women. Further, though it is one of the best ways to obtain feedback on behavioral interventions, focus groups can often be a difficult way of doing so. Women were most excited about the opportunity to share about life experiences with women who could relate, and sometimes had difficulty shifting their focus to UPLIFT intervention components.
Table 4.1. Demographic Characteristics of Focus Group Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n=18</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender Identity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cisgender Woman</td>
<td>12</td>
<td>66.7%</td>
</tr>
<tr>
<td>Transgender Woman</td>
<td>6</td>
<td>33.3%</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>18</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Age in years (mean = 49)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>30-39</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>40-49</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>50-59</td>
<td>4</td>
<td>22.2%</td>
</tr>
<tr>
<td>60-65</td>
<td>3</td>
<td>16.6%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9th grade or lower</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>10th grade</td>
<td>1</td>
<td>5.5%</td>
</tr>
<tr>
<td>11th grade</td>
<td>1</td>
<td>5.5%</td>
</tr>
<tr>
<td>High school or GED</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>Some college</td>
<td>7</td>
<td>38.8%</td>
</tr>
<tr>
<td>Graduated college</td>
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<td>0</td>
</tr>
<tr>
<td>Some graduate or professional school</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Completed graduate or professional school</td>
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<td>0</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$0-$4,999</td>
<td>3</td>
<td>16.6%</td>
</tr>
<tr>
<td>$5,000-$9,999</td>
<td>4</td>
<td>22.2%</td>
</tr>
<tr>
<td>$10,000-$14,999</td>
<td>3</td>
<td>16.6%</td>
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<td>$15,000-$19,999</td>
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<td>$20,000-$24,999</td>
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<td>33.3%</td>
</tr>
<tr>
<td>$25,000-$29,999</td>
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<td>0</td>
</tr>
<tr>
<td>$30,000-$34,999</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>$35,000+</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Relationship Status</strong></td>
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<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>11</td>
<td>61.1%</td>
</tr>
<tr>
<td>Not married, but living with a partner</td>
<td>3</td>
<td>16.6%</td>
</tr>
<tr>
<td>Married</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>4</td>
<td>22.2%</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Years since diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>5-10</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>10-15</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>15-20</td>
<td>5</td>
<td>27.7%</td>
</tr>
<tr>
<td>20+</td>
<td>7</td>
<td>38.8%</td>
</tr>
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</table>
Table 4.2. Focus Group Participants- Patient-Health Questionnaire-9 Scores

<table>
<thead>
<tr>
<th>PHQ-9</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9.235</td>
<td>3.052</td>
<td>5-14</td>
</tr>
</tbody>
</table>
Table 4.3. Major themes from focus group reactions to UPLIFT

<table>
<thead>
<tr>
<th>Themes</th>
<th>Comments</th>
<th>Adaptation Decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptability</td>
<td>Really like this</td>
<td>No major changes to exercises</td>
</tr>
<tr>
<td></td>
<td>“It teaches you patience with life”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty understanding</td>
<td>Teaching too text-heavy</td>
<td>Changed wording to simplify</td>
</tr>
<tr>
<td></td>
<td>Don’t really understand what is being said</td>
<td>Lowered reading level in Sessions 1 and 2</td>
</tr>
<tr>
<td></td>
<td>Manual print needs to be bigger</td>
<td>Screened for visual impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercises and Content</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation</td>
<td>Body scan might be too detailed and lengthy</td>
<td>Will ask in expert review</td>
</tr>
<tr>
<td></td>
<td>Typical ways of relaxing include crafting and music</td>
<td>Incorporate jazz music in Seeing and Hearing Exercise</td>
</tr>
<tr>
<td>Poems and Quotes</td>
<td>Can relate to my life</td>
<td>Kept all poems and quotes, no changes</td>
</tr>
<tr>
<td></td>
<td>Really like these</td>
<td></td>
</tr>
<tr>
<td>Pebble Exercise</td>
<td>Pebble was offensive to some participants</td>
<td>Replaced with “shell”</td>
</tr>
<tr>
<td>Audio Files for Meditation</td>
<td>Probably wouldn’t listen to it on my own</td>
<td>Didn’t use audio files, will consider for future</td>
</tr>
<tr>
<td>Practice</td>
<td>Should consider putting audio files on YouTube</td>
<td></td>
</tr>
<tr>
<td>Delivery Format-Phone</td>
<td>Might prefer in-person to see/trust who is teaching</td>
<td>Conference call groups best</td>
</tr>
<tr>
<td></td>
<td>Phone provides more privacy</td>
<td>Helps to alleviate transportation barriers</td>
</tr>
<tr>
<td></td>
<td>Don’t want everybody in my business and knowing I’m (HIV) positive</td>
<td>Reminds of prayer group lines for church</td>
</tr>
<tr>
<td>Recruitment for UPLIFT</td>
<td>Flyers in the clinic, just like for focus groups</td>
<td>Posted in clinic for 2nd phase</td>
</tr>
<tr>
<td></td>
<td>Word-of-mouth</td>
<td>Shared with participants who gave permission to be contacted post-screening</td>
</tr>
<tr>
<td></td>
<td>Tell health educator who is well connected</td>
<td>Flyers sent directly to specific health educators</td>
</tr>
<tr>
<td>Incentive Type if mailed</td>
<td>Prefer Visa gift cards can use anywhere</td>
<td>Offered Wal-Mart and Kroger gift cards</td>
</tr>
<tr>
<td></td>
<td>Would take Wal-Mart gift cards</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some would do without additional incentive</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 5

PROCESS EVALUATION OF PROJECT UPLIFT, A MINDFULNESS-BASED COGNITIVE THERAPY INTERVENTION FOR AFRICAN AMERICAN WOMEN LIVING WITH HIV/AIDS IN GEORGIA

\[1\] Hunter-Jones, J, Gilliam, S, Brown, D, Davis, C. To be submitted to *AIDS care*. 
Abstract

PLWHA experience depression at higher rates than the general population. According to current literature in this area, AAWLWHA (AAWLWHA) tend to be “silent” about their experiences of depression and therefore, depression among this group tends to go undiagnosed and untreated. Furthermore, there is a need for evidence-based contextualized interventions addressing depression among AAWLWHA. In the current study, the investigator aims to conduct two open trials with AAWLWHA to examine acceptability and feasibility of the adapted intervention, Project UPLIFT, an evidence-based intervention for reducing stress, anxiety, and depression by use of mindfulness-based cognitive therapy (MBCT) techniques. Women recruited for the open trials will be enrolled to one of two groups based on their gender identity, cisgender or transgender, to receive 8 weeks of one-hour phone intervention sessions, as well as participate in pre-test and post-test assessments. Additionally, following each UPLIFT intervention phone group, women will be asked to answer three questions regarding acceptability of the program. Project UPLIFT has been used for both the prevention and treatment of depression for people with epilepsy; the intervention is delivered by phone, cost-effective, and easily adapted for other chronic illness populations. The program provides a novel opportunity for adaptation and evaluation with a vulnerable group. In open trials, AAWLWHA (both cisgender and transgender) were highly satisfied with the intervention, and it was found to be feasible for cisgender women, though it seemed to be less feasible in its current state for transgender women.
Introduction

Mindfulness-based stress reduction (MBSR), influenced by the practice of “mindfulness” (being intentionally attentive in the present moment non-judgmentally) incorporates techniques of learning to focus and calm oneself to better cope with stress or illness. MBSR has shown treatment efficacy across a variety of populations experiencing chronic physical conditions (Carlson, 2012). Additionally, the techniques of mindful meditation and MBSR can efficaciously mitigate some HIV treatment side effects, psychological distress, (Duncan et al., 2012; Jam et al., 2010; Moskowitz et al., 2015) and improve CD4 counts. (Creswell et al., 2009; SeyedAlinaghi et al., 2012). A recent review on mindfulness-based therapies for persons living with HIV or AIDS (PLWHA) highlighted only one study that has utilized mindfulness-based cognitive therapy (MBCT), an MBSR-inspired intervention based on the tenets of both mindfulness and cognitive-behavioral therapy, with adults aging with HIV. The investigators of this study found reductions in psychological stress, anxiety, and depressive symptoms as well as an improvement in CD4 counts in intervention participants (Gonzalez-Garcia, Ferrer, Borras, Muñoz-Moreno, et al., 2013; Yang et al., 2015).

AAWLWHA represent approximately 64% of all new HIV infections among women, have been reported as experiencing more symptoms of depression than other subgroups of PLWHA, and often have their mental health unaddressed and untreated (CDC; (Moneyham et al., 2000); (Cook et al., 2014; Cook et al., 2006). A critical barrier to addressing the mental health of African American women living with HIV is a cultural “silence” among this group, particularly related to mental health. “Silencing the self” is a theory that was developed to describe the tendency of African American women living
with HIV to resist disclosing the experience of depressive symptoms for fear of burdening the family, distracting from the responsibility to care for the family, and/or appearing “weak” (DeMarco & Lanier, 2014; Lanier & DeMarco, 2015). Much research has characterized predictors and correlates of depression among African American women living with HIV; findings demonstrate the experience of depression in this group as particularly influenced by trauma histories, social support, family stress, and the importance of spirituality and spiritual wellbeing. (Ball et al., 2002; Braxton et al., 2007; Brownley et al., 2015; Dalmida et al., 2011, 2012; Johnson et al., 2003; Jones et al., 2003; Owens, 2003; Szapocznik et al., 2004; Whitehead et al., 2014). Yet there is a substantial gap in scientific knowledge about the unique experiences of African American women living with HIV. Despite the negative impact of depression on treatment adherence and retention in care, depression often goes undiagnosed, unaddressed, and untreated among these women (National Institute of Mental Health (U.S.)). Very few interventions have been designed to address depression for this group, and evidence-based interventions for African American women living with HIV are urgently needed.

Literature supports that mindfulness-based therapies may be a promising avenue for intervening with comorbid HIV/AIDS diagnoses and co-occurring mental health disorders. Furthermore, a review of technology-delivered interventions for PLWHA suggest that dissemination of such programs might be a necessary mode of delivery for vulnerable groups of PLWHA (Kempf et al., 2015), such as African American women living with HIV. Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) is an MBCT intervention that has shown efficacy in reducing stress, anxiety, and depressive symptoms in people with epilepsy and with cystic fibrosis. (Thompson et
al., 2015; Thompson et al., 2010; Walker et al., 2010) The intervention is evidence-based and cost-effective, delivered over 8 weekly sessions, and administered in the past remotely-by telephone or the web. Due to the success of MBSR and MBCT interventions used with other HIV-seropositive populations, (Carlson, 2012; Creswell et al., 2009; Gonzalez-Garcia, Ferrer, Borras, Muñoz-Moreno, et al., 2013; Jam et al., 2010; Moskowitz et al., 2015; Riley & Kalichman, 2015; Robinson et al., 2003; SeyedAlinaghi et al., 2012; Yang et al., 2015) and the success of Project UPLIFT for other chronic disease populations, (Thompson et al., 2015) the proposed research will address an important problem by adapting and evaluating an innovative, evidence-based tele-therapy intervention for the treatment of depression among AAWLWHA.

MBCT, the basis of Project UPLIFT, draws from a number of empirically evaluated theories and treatment modalities. The first of several theoretical foundations that led to the development of MBCT is Barnard and Teasdale’s “Interacting Cognitive Systems” (ICS) theory (Barnard & Teasdale, 1991). ICS links depression and depression relapse to a person’s tendency to use one of two modes of mind: the “doing” mode or the “being” mode. The “doing” mode is driven by goals towards change when there is a discrepancy between how a person desires a situation to be and how the current situation truly is. The “being” mode, in contrast, is not focused towards change but in accepting the present regardless of what it is. According to ICS, being able to transition from one mode to the next, as well as being meta-cognitively aware (being able to recognize negative thoughts as impermanent) – are characteristics of persons less likely to be depressed or to become recurrently depressed (Barnard & Teasdale, 1991; John D Teasdale, 1993; John D Teasdale et al., 1995; J. D. Teasdale et al., 2000) Segal and colleagues have also contributed to the development of MBCT by detailing how those
who have once experienced major depression are more likely to have recurring depression as a result of negative thinking patterns that are distinct from those who have not experienced major depression (Segal & Walsh, 2015).

In addition, cognitive-behavioral therapy (CBT) is one of the two integrated tenets of MBCT. CBT is recognized as an effective treatment for clinically diagnosed depression. (Beck & Dozois, 2011) The second integrated tenet of MBCT is mindfulness, a skills-based practice that involves heightened awareness of one’s thoughts or experiences. Mindfulness interventions, such as mindfulness-based stress reduction (MBSR), often involve meditational exercises derived from Buddhist practice, and had an influence on the development of MBCT. MBSR was based on Lazarus and Folkman’s Theory of Transactional Model of Stress and Coping. The Theory of Transactional Model of Stress and Coping discusses the response to stressors as appraisals (Folkman, 1984; Lazarus, 1974). The first appraisal usually relates to the examination of how someone perceives they will be impacted and their responsibility in contributing to the stressor; the second appraisal relates to one’s perception of control over the outcomes, emotions, and ability to do something about the stressor. These appraisals drive the coping effort of an individual, therefore impacting the propensity for experiencing depression (Folkman, 1984). This model of Stress and Coping is considered to have a substantial theoretical influence on MBCT, the basis of Project UPLIFT. The eight Project UPLIFT intervention sessions integrate the theoretical foundations and influences of ICS, MBSR, MBCT (as influenced by both mindfulness and cognitive behavioral therapy), and The Transactional Model of Stress and Coping as evident by the intervention session titles and related content (see Table 1).
No known study has evaluated the utility of a mindfulness-based cognitive therapy intervention for AAWLWHAs. The purpose of the current study was to conduct two open trials of the adapted UPLIFT materials, and to collect data demonstrating its acceptability and feasibility for AAWLWHAs.

**Methods**

Once approval from the university Institutional Review Board was obtained, women were recruited from a specific AIDS-service organization (ASO) that provides care to individuals who are HIV-seropositive in the local Atlanta, Georgia and surrounding areas. Recruitment flyers were posted throughout the agency, and shared with staff connected to the target population of interest. The flyer provided contact information for calling to get more information or be screened for enrollment in the study.

In order to participate in the study, women had to be 18 years of age or older, identify as Black or African American, identify as a woman, have previously received an HIV or AIDS diagnosis by a healthcare provider, be mild to moderately depressed (as defined by a total score ranging from 5 to 14 on the PHQ-9 as a screening measure), cognitively apt, speak English fluently, and indicate that they had NOT participated in previous UPLIFT focus groups where formative feedback on the intervention was solicited. Women were determined ineligible for indicating no/minimal or severe depressive symptoms (a score of 0-4 OR 15 or greater on the PHQ-9), suicidal ideation within the past month, or cognitively impaired such that they were unable to provide informed consent to participate in this research.

Women who were interested were explained that if eligible and consented, they would be asked to participate in three main study components: 1) a pre-test preceding
UPLIFT sessions; 2) an open trial group of 8 UPLIFT sessions, once per week; and 3) a post-test following UPLIFT sessions. Every woman who was consented for participation completed a pre-test survey that lasted between 30 and 45 minutes. The pre-test survey was administered over the phone by a graduate public health student using Qualtrics. Following the completion of the pre-test, women were asked to participate in one of two UPLIFT groups; as a result of lessons learned in focus group administration and because this research is focused on process evaluation- there was no group randomization. Women were enrolled into one of two groups based on their self-reported gender identity. A designated time was selected for each of the two groups. The designated time was a one-hour time slot that worked best for the majority of the participants in each group, to call into a conference line for an hour once a week for 8 weeks. The conference call line and access code was different for each of the two groups, allowed for audio-recording on each call, and monitoring of call-in numbers, as well as call-in times for each number and call drops. Prior to the first week’s session, women were mailed an UPLIFT intervention manual, a copy of the consent form for which they verbally consented by phone, and dates and times for UPLIFT sessions, and specific call-in instructions for each week’s UPLIFT conference session.

In addition to participating in the weekly call, women were asked to call into a separate voicemail account following each weekly call to leave a message providing feedback from that day’s session. Specifically, women were asked to answer one of three questions each week. The questions were included in the UPLIFT intervention manual sent to each participant, and were as follows: 1) What did you like? 2) What didn’t you like?; and 3) What would you change? about today’s UPLIFT session. For the
completion of both weekly tasks (the call and voicemail feedback), women were incentivized with a $10 Wal-Mart or Kroger gift card of their choice.

After the completion of the 8-week UPLIFT program, women were asked to participate in a post-test survey. The post-test survey lasted approximately 45 minutes, and was administered over the phone by a graduate public health student using Qualtrics—just as the pre-test was. For the pre-test and post-test, women received a $15 Wal-Mart or Kroger gift card of their choice. Therefore, women were incentivized up to $110 for their time and participation with the amount of incentive varying based on session participation. Gift cards were mailed to participants at three intervals over the course of the study: following the initial pre-test, after the first 4 sessions of UPLIFT, and finally, following the post-test period.

Screening measures for participation in the study were as follows. Demographic questions were asked to assess whether individuals met the basic criteria for participation to include, age, gender identity, race/ethnicity, and state of residence. Women had to be 18 years or older, identify as a woman, as African American (though they could have identified with other ethnic groups in addition), have been diagnosed with HIV/AIDS by a healthcare provider, and be residing in Georgia.

Cognitive status/mental stability was assessed by use of the T-MMSE (Telephone-Mini Mental State Examination), (Newkirk et al., 2004) The T-MMSE is an adapted version of the Mini-Mental State Examination and is used to measure cognitive status by asking a battery of questions related to orientation to time and place, attention, naming, repetition, recall, and a three-stage command. This measure takes approximately 5 to 10 minutes to administer, and has been shown valid and effective in assessing one’s cognitive state.
Symptoms of depression were assessed by use of the Patient Health Questionnaire-9 (PHQ-9), a 9-item instrument clinicians use to screen for depressive symptoms (Kroenke et al., 2001). Women will be excluded from participation in focus groups if they receive a total score of 4 or less (indicating little or no distress), OR 15 or greater (indicating moderately severe to severe distress), (Kroenke et al., 2001). This will allow for the recruitment of women who are minimally to moderately depressed, but not severely depressed. Referrals were provided as appropriate.

Suicidal intent or planning within the past month was assessed by utilizing two revised items from the Youth Risk Behavior Survey, (Eaton et al., 2012): (1) During the past month, did you ever seriously consider attempting suicide? (2) During the past month, did you make a plan about how you would attempt suicide? Women were excluded if suicidal ideation was indicated. Referrals were provided as appropriate.

The following describes the evaluation measures utilized on the pre-test. Knowledge and skills related to mindfulness and cognitive behavioral techniques were assessed using a measure used with samples of persons with epilepsy (PWE) in previous evaluations of Project UPLIFT (Thompson et al., 2010); sample coefficient α for this sample was .922. There were 18 knowledge items; one example is “Even mild satisfaction from one’s own experience can result in positive mood”, responses include true-false response options. There were 14 skills items querying how one perceives their ability to do for example, the following, “Monitor your thoughts by keeping a record or diary...”. The Likert-scale response options ranged from 1 (Poor) to 5 (Excellent). Knowledge items were evaluated on the accuracy of response; higher scores on skills items indicated a greater perception of skill.
Mindful attention and awareness was assessed by utilizing the MAAS, a 15-item measure designed to evaluate one’s openness, receptiveness, and awareness to attending to the present- core characteristics of mindfulness; sample coefficient α for this sample was .884. (K. W. Brown & Ryan, 2003; MacKillop & Anderson, 2007). One item on this measure is, “I break or spill things because of carelessness, not paying attention, or thinking of something else”. Items were reverse coded; therefore, higher scores indicate more mindful attention and awareness.

Depressive symptoms were assessed by utilizing a modified version of the Beck Depression Inventory (mBDI), sample coefficient α for this sample was .867 (Beck & Steer, 1984; Beck et al., 1996; Dori & Overholser, 2000). This measure includes 21 original BDI items as well as scaled responses ranging from 0 (positive) to 4 (severe), higher scores indicate greater depressive symptoms. The measure’s prompt reads, “For the following questions, please indicate how you currently feel in the moment?”, and responses include a series of statements with options ranging from, for example, 0 (I do not feel like a failure) to 3 (I feel like I am a complete failure as a person). During screening, patients were enrolled if they indicate mild depression, yet excluded if severely depressed. Therefore, symptoms of depression on the mBDI at pre-test were expected to be potentially low. The modified version of the BDI is most appropriate because of its’ ability to detect subtle differences in depression (Dori & Overholser, 2000).

Anxiety symptoms was assessed by utilizing the Beck Anxiety Inventory (BAI), (Beck et al., 1988), a 21-item measure querying anxiety experienced in the past week; sample coefficient α for this sample was .919. An example item from this measure reads, “During the past month, including today, how often have you been bothered by any of
the following symptoms?”, one of which that reads, “numbing or tingling”. The measure includes response choices that range from 0 (Not at all) to 4 (Severely), with higher scores indicating greater anxiety symptoms.

Symptoms of stress were assessed by utilizing the Perceived Stress Scale (PSS-10); sample coefficient α for this sample was .724 (Cohen, 1988), a 10-item measure assessing the “perception” of stress experiences in the past month. One item reads, “In the last month, how often have you felt that you were unable to control the important things in your life?”. The measure includes response options that range from 0 (Never) to 4 (Very Often), with higher scores indicating greater stress symptoms.

Symptoms of Post-traumatic Stress Disorder (PTSD) were assessed by utilizing the PTSD-8); sample coefficient α for this sample was .841 (Hansen et al., 2010). The measure contains 8 items, consisting of 4 Intrusive items, 2 Avoidance items, and 2 Hypervigilance items. Respondents are asked to think of a trauma they’ve experienced, and to specify how often they have experienced the symptoms listed such as, “recurrent thoughts or memories of the event.” It includes Likert-scale response options that range from 0 (not at all) to 3 (most of the time), with higher scores indicating greater traumatic stress symptoms. Respondents were also given the opportunity to specify whether they had no traumatic event to reference.

Coping self-efficacy was assessed by utilizing The Coping Self-Efficacy Scale (CSES); sample coefficient α for this sample was .965 (Chesney et al., 2006). The measure is a 26-item assessment of perceived self-efficacy for coping, particularly related to challenges and threats that may arise. Items present scenarios such as “when things aren’t going well for you, or when you’re having problems”, how confident one feels for example to, “talk positively to yourself”. The measure includes response choices
that range from 0 (cannot do at all) to 10 (certain can do) with higher scores indicating greater coping self-efficacy. The measure has been used with a number of HIV-infected samples (Rodkjaer et al., 2014), and may be of particular relevance as it relates to the theoretical significance of appraisals in the Transactional Model of Stress and Coping which is a foundational influence of MBCT.

Satisfaction with life was assessed by utilizing the SWLS-5; sample coefficient α for this sample was .743 ((Diener, Emmons, Larsen, & Griffin, 1985). The measure is a 5-item assessment of self-reported satisfaction with life. One item on the scale reads, “So far I have gotten the important things I want in life”. Response choices on the scale range from 1 (Strongly disagree) to 7 (Strongly agree). Higher scores indicate greater satisfaction with life.

Perceived availability of social support was measured by use of the PASS scale, a 7-item scale that assessed whether or not respondents perceive that they have a specific kind of support available should they need it (Newland & Furnham, 1999). The scale included items such as, “Would someone be available to talk to you if you were upset, nervous, or depressed?” The response options ranged from 1 (Definitely not) to 5 (Definitely yes). Higher scores indicate favorable perceptions of available social support.

Self-reported quality of life was measured using one item from the World Health Organization’s Quality of Life measure. The item used was, “How would you rate your quality of life?”. The response options were on a 5-point Likert scale ranging from, “Very Poor” to “Very Good”. Higher ratings on this item indicated better self-rating of quality of life.

Medication adherence was measured by the use of one item from the HIV Medication Utilization measure (Meade et al., 2009). The item used was, “In the past 3
months, how would you rate your adherence to medication as your doctor has prescribed it?” The response options were on a 5-point Likert scale ranging from, “Very Poor” to “Very Good”. Higher scores on this item indicated better self-reported medication adherence.

In addition to the above evaluation measures, the following measures were included on the post-test survey only. In order to assess acceptability of the intervention, an 8-item Client Satisfaction Questionnaire (CSQ) was used, (Attkisson & Zwick, 1982). One question from this measure was, “Did you get what you wanted from Project UPLIFT?” with responses ranging from “No, definitely not” to “Yes, definitely”. Higher scores on the client satisfaction questionnaire indicated greater satisfaction with UPLIFT. Qualitative data on the acceptability of the intervention was retrieved from the audio voicemail recordings of feedback on UPLIFT after each individual session.

In order to assess feasibility, attendance records and a 22-item process evaluation measure was used. This measure has been used with PWE samples in evaluating the efficacy of Project UPLIFT, (Walker et al., 2010). One item from the process evaluation measure read, “The phone calls kept my attention” with responses ranging from 1 (Strongly disagree) to 5 (Strongly agree). Higher scores indicated better agreement with the UPLIFT process and logistics. Additionally, facilitators were asked to provide feedback on each UPLIFT session following facilitation. Facilitators were asked to answer the following questions as a component of feedback for each session, “How engaged and interested were participants?”, and “How much did participants seem to understand the material?”, with response options 1 “Very disengaged” to 4 “Very engaged” and 1 “Not at all” to 4 “Very well”, respectively. Facilitators were also asked to provide an “overall session rating” where responses ranged from 1 “Poor” to 4
“Excellent”. High scores indicated greater engagement, a perception of greater participant understanding of session material, and a better overall session, respectively.

In order to assess preliminary efficacy of the intervention, changes in stress, PTSD, anxiety, and depression for which measures will be described in detail below. Additionally, changes in knowledge and skills will be compared from pre-test to post-test.

**Results**

Of the 23 women who were screened to participate in the UPLIFT open trials, 18 women were enrolled into 2 separate groups (1 for cisgender women and 1 for transgender women). Of the 18 women enrolled, only 15 women began and completed the intervention (see Table 1). Each of the 15 women enrolled identified as an African American woman. Two women identified as having mixed African American and Caucasian ethnicity, and another identified as having mixed African American and Hispanic ethnicity (see Table 1). The mean age of open trial participants was 50.1 years, ranging from their 20s to their 60s. Regarding education, more than half the sample had obtained at least a high school diploma or GED. Most of the sample had annual incomes under 20K, and one additional participant reported an income between 25K and 35K. Most of the women were either “Single, Never Married” or “Not married, but living with a partner”. Years since HIV/AIDS diagnosis ranged from within the past 5 years to being diagnosed more than 20 years prior. The mean score for depressive symptomology based on the PHQ-9 was 8.4 (SD=3.41), indicating moderate distress based on self-reported depressive symptomology (see Table 2).

A pre-test was administered prior to the first UPLIFT session. Of the 18 women who originally enrolled in the study, two women dropped before the start of Session 1 in
Group A, and one woman dropped before the start of Session 2 in Group B. All 15 women who began the UPLIFT open trials completed the post-test following Session 8 of UPLIFT. The results described below include the 15 women who completed both the pre-test and post-test assessments.

Acceptability

In addition to participating in 8 one-hour weekly sessions by conference call, participants were required to provide feedback following each session by leaving a voice message in a designated confidential line answering 3 questions: 1) What did you like? 2) What didn’t you like?; and 3) What would you change?. This feedback would serve as data on acceptability/satisfaction of each individual session. Women who did not leave feedback after weekly sessions were sent a text reminder or given a call asking that they call in to provide their feedback. Overall, there was no feedback provided indicating that women disliked or would change any portion of the UPLIFT intervention (see details in Table 3). Women consistently shared that they were pleased with the sessions and rarely had suggestions for change. Women did however, provide feedback indicating that they were displeased with the sound quality of the conference calls which seemed to be related to having multiple people on the line with background noise. For example, one woman shared, “Everything is great. I just wish people would be respectful and put their phones on mute. There are dogs barking, babies crying, all that”. This seemed to be a repetitive theme throughout the first several sessions of the UPLIFT intervention for both Groups A and B. However, the complaints about the background noise began to subside around Week 4 of the intervention with one woman even saying, “Today’s session was great, and everybody had their phone muted. It was beautiful.” Another complaint unrelated to the UPLIFT intervention specifically, was the frequency of
inquiries about gift card incentives. In one participant’s feedback, she explained, “I really like the sessions, but for an hour, we should receive $15, not $10.” Incentives for UPLIFT session participation was a topic raised continuously throughout the 8 weeks of UPLIFT particularly by Group B participants. During one UPLIFT call session, after the facilitators thanked the women for a great session and stated that they would speak with them the next week, one participant loudly proclaimed, “Another $10 in my pocket!”

**Quantitative Assessment of Satisfaction**

The mean Client Satisfaction Questionnaire score was 31.5 for Group A (SD=0.76) out of a possible 32, and 31.00 for Group B (SD=1.41), (see Table 4). For all questions, the majority of participants most frequently chose the response of “highest degree of satisfaction”. When asked to what extent Project UPLIFT met their needs, two-thirds of the sample responded, “almost all of my needs have been met” while another third responded, “most of my needs have been met”. In addition to assessing the overall satisfaction of UPLIFT, participants were asked whether they would participate in UPLIFT at no cost, but with no incentive; all participants but one said that “yes” they would participate at no cost, but with no incentive. When asked how UPLIFT could be improved despite willingness to participate with no incentive, most women said that nothing could be done to improve satisfaction. One woman said, she “would like more details about mindfulness” in response to what could make her even more interested.

**Feasibility**

Attendance was a critical measure of feasibility in the current study. Ten women were initially recruited for Group A (cisgender women) of the intervention; 8 women were initially recruited for Group B (transgender women). Two women dropped before
the start of Session 1 in Group A, and one woman dropped before the start of Session 2 in Group B. Of the 8 people in Group A (cisgender women) who began the intervention beginning at Session 1, all 8 were considered “completers” as they each completed more than 80% of the UPLIFT sessions. Half of the women attended 100% of the sessions. Each call for Group A throughout the 8-week intervention included at least 7 participant members. Of the 7 people in Group B (transgender women) who began the intervention beginning at Session 1, 6 women were considered “completers”. Each of these 6 women completed 100% of the UPLIFT sessions. One woman missed 3 UPLIFT sessions due to hospitalization, but continued after release and followed through consistently until the last session. Each call for Group B throughout the 8-week intervention included at least 6 participant members on each session call.

In addition to attendance records, a 22-item process evaluation measure was included on the post-test survey. The process evaluation included items that asks about individual elements of the UPLIFT intervention. For each intervention component, participants were asked to rate their value on a 5-point Likert scale that ranged from “1-not at all valuable” to “5-very valuable”, while other items included response options that ranged from “1-strongly disagree” to “5-strongly agree”. When observing responses from all 15 participants of UPLIFT, we found that among all the intervention components, “group discussions” and being “comfortable using the phone for this program” seemed to be most favored. All 15 participants rated these components using the highest ratings of “5-very valuable”, and “5-strongly agree” for these two components, respectively. When asked, “Did you find it difficult to participate in these sessions?”, only one woman responded “yes”. Based on the process evaluation measure including response options that could total a maximum of 110, higher scores
represented more agreement that certain UPLIFT components were considered most valuable or that women strongly agreed were useful or feasible. The mean total score for Group A was 91; the mean total score for Group B was 85.14.

In general, facilitators seemed to find UPLIFT to be feasible for women. As it relates to time management, the main facilitator and co-facilitator were able to successfully complete every component of the UPLIFT intervention, and had no difficulty completing the activities in the time allotted. There were a couple sessions where they finished a few minutes early and one session, Session 7, ended quite early (about 20 minutes prior to the end time) for both Groups A and B- potentially due to a lack of discussion/participation. As an additional measure of feasibility, both facilitators were asked to provide feedback after each individual UPLIFT session for Groups A and B independently. Quantitative ratings were requested in addition to qualitative feedback. Across all ratings for all 8 sessions of UPLIFT, Group A received higher average ratings on feasibility than did Group B. Group A session participants received an average rating of 3.9 on “engagement” where scores ranged from 1 (not very engaged) to 4 (very engaged), an average rating of 3.6 on “understanding” of session material where scores ranged from 1 (not at all) to 4 (very well), and received an average rating of 3.6 as an overall session rating where scores ranged from 1 (poor) to 4 (excellent). Group B session participants received an average rating of 3.2 on “engagement” where scores ranged from 1 (not very engaged) to 4 (very engaged), an average rating of 3.2 on “understanding” of session material where scores ranged from 1 (not at all) to 4 (very well), and an average rating of 2.9 as an overall session rating where scores ranged from 1 (poor) to 4 (excellent). It should be noted that Group B ratings seemed to increase around Session 4.
Similar to qualitative feedback from women after each week’s sessions, the most common complaints shared by facilitators particularly from sessions 1 to 4 was the difficulty in hearing clearly and the number of background distractions due to women having their phones unmuted during teaching or leading exercises. Given that the primary researcher listened to the audiotaped groups and provided weekly feedback to facilitators, there was discussion regarding background noise and reminders to women to place their phones on mute during teachings and exercises where they were speaking. The problems with background noise seemed to decline around session 4 and continually declined to very minimal throughout the remainder of UPLIFT. In the final session, Session 8, women seemed to be extremely engaged in creating a Preventing Lapses Action Plan, and providing feedback to one another. This session ran over in both groups by 15 to 20 minutes.

As it relates to ease of facilitation, there were times where the facilitators believed that the group wanted to share personal examples and life stories, but what participants shared did not always relate directly to UPLIFT content. In particular, the facilitators shared that for exercises such as ARMed Against Distress, doing “reality checks”, “What-If’s”, and problem solving (primarily in Group B) - the groups seemed to have difficulty or challenges initially grasping the concept of the exercise. However, after some time or often during the next session and with some guidance from the facilitators, they seemed to get a better grasp of these exercises. In contrast, both groups seemed to both enjoy and grasp the relaxation and mindfulness exercises such as the Body Scan, Relaxing Muscles In Order, 3-minute breathing space. Though women seemed to appreciate participating in the Shell Exercise, facilitators shared that they seemed to have difficulty understanding its overall “meaning” and how it was connected to mindfulness.
Similarly, they struggled to give examples of other ways in which they could practice mindfulness in their everyday lives. Participants also had difficulty initially understanding the purpose of the Seeing and Hearing Exercise in Session 5, though some seemed eager to learn more and actively practice it. Although women seemed to have difficulty making a connection between mindfulness as what they were supposed to be doing and the actual mindfulness exercises, they seemed to really connect with the teaching content related to “being present” and observing “the present as a calm place” in Session 5. In the last session, Session 8, women seemed to be truly appreciative of the structure of the session allowing them to discuss what they had learned, plans moving forward, and showing appreciation to one another as participants of the group. It seemed that women enjoyed having the space to discuss and engage with one another, and believed the intervention would help them to control their tempers (as on specifically mentioned example).

Observed differences between Groups A and B were evident in facilitator feedback, and congruent in quantitative ratings of sessions on engagement, understanding, overall rating of sessions, and process evaluation data. Overall, facilitators seemed to have a difficult time with keeping Group B participants engaged and on task. One comment from a facilitator following Session 3 said, “I just don’t know if they are actually engaged with UPLIFT”. Another included a facilitator expressing that the participants seemed to often be disengaged from the material. Additionally, participants seemed to be often concerned about incentives for participation; this was observed on audio-recordings of sessions, in weekly feedback from individual participants, and in feedback from facilitators- where participants would discuss whether they had yet received their gift cards. There were a couple of disagreements
with participants on the line, though they both seemed to resolve fairly quickly. Further, obscene language was often used during sessions. It is difficult to ascertain whether this impacted engagement or participation for other group members. One participant did leave her weekly feedback sharing that she was isolated and ridiculed by one member in the group, and made to feel uncomfortable during that day’s group session.

To test the hypothesis that pre-test means and post-test means were equal, a paired samples t-test was performed for each measure. Prior to conducting the analysis, assumptions of normally distributed mean differences were examined. With assumptions satisfied, the null hypothesis of equal means on each measure was tested. Results on the measures described below can be found in Table 5.

**Depression**

Depressive symptoms were measured by use of the modified Beck Depression Inventory and mean scores decreased from pre-test to post-test in Group A (M = 15.50, SD = 11.40) to (M = 11.38, SD = 8.45). Cohen’s $d$ was estimated at 0.27 which demonstrates a small effect size. Group B’s depression scores also decreased from pre-test to post-test (M = 13.14, SD = 6.84) to (M = 8.71, SD = 11.91) with a small effect size of 0.35. As it relates to clinical significance, mean scores on depression for Group A decreased from a range of ‘Mild’ depressive symptomology to ‘Minimal’ depressive symptomology on the BDI. For Group B, mean scores on depression for Group B moved from in between the ‘Minimal’- ‘Mild’ depressive symptomology to ‘Minimal’ depressive symptomology.

**Anxiety**

Anxiety symptoms were measured by use of the Beck Anxiety Inventory and mean scores decreased from pre-test to post-test in Group A- (M = 20.50, SD = 14.10) to (M = 17.50, SD = 11.58) with a small effect size of 0.29. Group B’s anxiety mean scores
actually increased from \((M=14.71, \text{SD}=10.69)\) to \((M=15.57, \text{SD}=15.11)\) with an effect size of 0.04. As it relates to clinical significance, mean scores on anxiety, Group A’s scores decreased from higher mean scores in the ‘Moderate’ category to lower scores in the same category. Group B’s scores continued to linger near the ‘Mild’ category of anxiety symptoms.

**Stress**

Stress symptoms decreased in both groups. Group A scores \((M=17.75, \text{SD}=5.18)\) on the Perceived Stress Scale to \((M=16.13, \text{SD}=9.63)\) at post-test with an effect size of 0.13. Group B scores of \((M=13.71, \text{SD}=5.65)\) at pre-test decreasing to \((M=13.00, \text{SD}=5.54)\) with an effect size of 0.08. As related to clinical significance for stress symptoms, though mean scores decreased Group A’s scores remained in the ‘Moderate’ stress category, and Group B’s scores remained in the ‘Mild’ stress category even though both decreased.

**Knowledge**

As it relates to knowledge measured by the Knowledge and Skills measure utilized with previous samples of UPLIFT, Group A’s scores at pre-test increased \((M=12.13, \text{SD}=2.23)\) to \((M=12.25, \text{SD}=1.28)\) at post-test with an effect size of 0.04. Group B’s scores decreased from \((M=12.29, \text{SD}=1.50)\) to \((M=11.71, \text{SD}=1.60)\) at post-test with a small Cohen’s \(d\) effect size of 0.24.

**Skills**

As it relates to skills as measured by the Knowledge and Skills measure as mentioned above, Group A’s scores increased from \((M=53.75, \text{SD}=8.83)\) at pre-test to \((M=55.50, \text{SD}=7.93)\) at post-test with a medium Cohen’s \(d\) effect size of 0.52. Group B’s
scores increased from (M=51.29, SD=10.08) at pre-test to (M=57.86, SD=11.04) at post-test with a small Cohen’s $d$ effect size of 0.41.

**Mindful Attention and Awareness**

In measuring mindful attention and awareness, mindfulness improved from pre-test to post-test for Group A – (M=46.5, SD=11.75) to (M=53.75, SD=14.95) with a large Cohen’s $d$ effect size of 0.81. However, for Group B, scores decreased from (M=65.86, SD=12.28) at pre-test to (M=58.29, SD=14.94) with a small Cohen’s $d$ effect size of 0.36.

**Post-Traumatic Stress**

Post-traumatic stress was measured by use of the PTSD-8, and overall scores on symptoms (not displayed in Table 5) increased from (M=11.00, SD=6.76) at pre-test to (M=14.25, SD=5.90) at post-test among Group A with a small Cohen’s $d$ effect size of 0.35. For Group B, overall scores on post-traumatic stress symptoms decreased (M=12.67, SD=4.32) at pre-test to (M=10.14, SD=8.47) with a small Cohen’s $d$ effect size of 0.47. The PTSD-8 measure includes 3 subscales: hypervigilance, intrusion, and avoidance.

On the PTSD hypervigilance subscale, Group A’s mean scores increased (M=3.25, SD=1.75) at pre-test to (M=3.88, SD=1.96) at post-test with a small Cohen’s $d$ effect size of 0.20. Group B’s mean scores decreased (M=3.33, SD=2.50) at pre-test to (M=1.67, SD=1.86) at post-test with an effect size of 0.46. As it relates to clinical significance on this measure, having at least one item score $\geq 3$ meets the criteria for hypervigilance demonstrating Group A continuing to meet this criterion post-intervention based on mean scores, and Group B dropping below this and no longer meeting the criterion for hypervigilance post-intervention. It should be noted that as indicative by standard deviation, individual participants may not have met this criterion.
On the PTSD Intrusion subscale, Group A’s mean scores increased (M=4.75, SD=3.41) at pre-test to (M=6.75, SD=3.15) at post-test with an effect size of 0.42. Group B’s mean scores decreased substantially from (M=6.17, SD=1.17) at pre-test to (M=3.00, SD=3.69) at post-test with an effect size of 1.03 indicating that the magnitude of this effect is greater than one standard deviation from the mean score. As with PTSD Hypervigilance, individual scores of 3 or greater indicates criterion for intrusion on the measure.

On the PTSD Avoidance subscale, Group A’s mean scores increased (M=3.00, SD=2.20) at pre-test to (M=3.63, SD=2.62) at post-test with an effect size of 0.21. Group B’s mean scores also increased from (M=3.17, SD=1.83) at pre-test to (M=3.50, SD=2.95) at post-test with an effect size of 0.09. As previously described for the other subscales of this measure, individual scores of 3 or greater indicates criterion for avoidance on the measure.

Coping Self-Efficacy

On self-reported coping self-efficacy, mean scores increased from pre-test to post-test for Group A, but decreased for Group B. Scores for Group A increased (M=195.88, SD=46.48) at pre-test to (M=214.00, SD=26.23) with a large Cohen’s d effect size of 0.87. Scores for Group B actually decreased (M=209.29, SD=27.83) at pre-test to (M=204.86, SD=41.56) at post-test with a Cohen’s d effect size of 0.08.

Satisfaction with Life

Satisfaction with life scores for Group A increased (M=22.50, SD=6.78) at pre-test to (M=24.75, SD=4.71) at post-test with a small Cohen’s d effect size of 0.27. Scores for Group B decreased (M=24.43, SD=5.65) at pre-test to (M=21.71, SD=8.62) at post-test with a small Cohen’s d effect size of 0.24.
**Perceived Availability of Social Support**

Scores on perceived availability of social support increased for Group A (M=28.38, SD=5.45) to (M=32.50, SD=3.12) with a large Cohen’s $d$ effect size of 0.80. Conversely, scores on social support decreased for Group B (M=30.71, SD=3.64) to (M=28.86, SD=5.79) with a small Cohen’s $d$ effect size of 0.40.

As a result of only one item being utilized from each of the measures below, these results are not displayed in Table 5, but changes from pre-test to post-test are described below:

**Quality of Life**

Quality of life was measured by use of one item from WHO’s QOL scale. The mean score on this item for Group A was 4.00 (0.76) at pre-test and decreased to 3.88 (0.84) at post-test with an effect size of 0.15. The mean score on this item for Group B was 4.00 (0.58) at pre-test and increased to 4.29 (SD=0.95) at post-test with an effect size of 0.26.

**Medication Adherence**

One item was used to assess medication adherence. The mean score on this item for Group A was 4.75 (0.46) at pre-test and increased to 5.00 (0.00) with an effect size of 0.54. The mean score on this item for Group B was 5.00 (0.00) at pre-test and decreased to 4.86 (SD=0.38) with an effect size of 0.38.

**Discussion**

There is a lack of behavioral interventions that address the psychosocial functioning of vulnerable groups such as PLWHA. AsWLWHA are at risk for experiencing anxiety and depression in ways that may impact their quality of life, as well as treatment adherence. Unfortunately, this group is also prone to not addressing such
mental and behavioral health concerns placing them at even further risk to the
detriment of a disease that with such advanced treatment options, could have a
prognosis of long life and productivity.

In order to address the lack of available interventions in this area, the current
investigator sought to evaluate the acceptability and feasibility of an adapted version of
Project UPLIFT, an evidence-based program originally designed for addressing
depression in persons living with epilepsy. The intervention is a distance-delivered
MBCT intervention that has shown to be effective in improving mental health among
PWE. The current research attempts to assess UPLIFT's utility towards these goals for
AAWLWHA in two phases: the first was via focus groups with and expert interviews
gathering formative feedback on UPLIFT, and the second was via the open trials
described in this paper.

Regarding acceptability, women seemed to be satisfied with the UPLIFT
intervention overall. Ratings on the Client Satisfaction Questionnaire were extremely
high. Additionally, satisfaction with the intervention was assessed via weekly voice
messages responding to three questions. These questions allowed for the researcher to
assess what women were satisfied with, dissatisfied with, and what could be improved or
further adapted. Women mostly had concerns about incentive, when they would receive
it and whether it could be increased, as well as distracting noises while on the session
call. Regarding incentive, it should be noted that most participants had an annual
income of 20K. It is possible that women are experiencing financial strain. However,
this could also provide insight into women’s motivation to participate in the project.
Transgender women seemed to be highly motivated by the expectation of receiving an
incentive for participating which may have impacted their overall engagement during
UPLIFT sessions. This should be a consideration for future studies with this population, and should provide context for the consideration of UPLIFT being used with this group.

As it relates to feasibility of the intervention, attendance was an indication that phone groups were feasible for both cisgender and transgender AAWLWA though such findings are limited to the small sample of women living in Georgia. Upon further assessment utilizing a process evaluation measure after the UPLIFT open trials as well as feedback from facilitators weekly, it seemed as though there were some exercises for which women had difficulty with overall. The exercises related to mindfulness were welcoming and seemed to be intriguing, but women still seemed to have trouble “connecting the dots” and understanding the true meaning of the exercises they were engaging in. This echoes previous UPLIFT research with PWE where during formative evaluation participants alluded to the importance of making connections and direct links between their experience and the purpose of UPLIFT exercises (Walker et al., 2010). In addition, in the open trials of UPLIFT for AAWLWA, there seemed to be a difference in the engagement of transgender women as compared to cisgender women in ways that impacted the success of group facilitation from the perspective of the group facilitators. Further, incentives seemed to be a huge concern for transgender women which may have impacted engagement with the material.

The outcome evaluation conducted in this study supported the differences observed in the two groups and feasibility of the intervention. Regarding outcomes of interest, where mean scores moved in the expected direction from pre- to post-test for cisgender women, these scores moved in the opposition to what was hypothesized for transgender women on a number of outcomes. These outcomes included knowledge,
mindful attention and awareness, anxiety, coping self-efficacy, satisfaction with life, and perceived availability of social support.

Too little is known about the success of MBCT interventions with this population to speak to its effectiveness as a mechanism for improving psychosocial functioning. Even less is known about the mental health experiences of African American transgender women living with HIV/AIDS. However, based on the promise of MBSR and MBCT for PLWHA, it is worth further exploration. For cisgender women, it seems that UPLIFT should be further explored by potential use of a randomized, controlled trial with larger samples of cisgender AAWLWHA. For transgender women, it is possible that either more qualitative exploration is needed regarding the mental, emotional, and behavioral health of this population, or UPLIFT may require additional formative feedback to make appropriate adaptations to the intervention tailoring it specifically for this group.

**Limitations**

The main limitation of this study to be noted is its small sample size. Given that only 15 women participated and completed UPLIFT sessions, statistical significance demonstrating intervention effects is difficult to achieve. Further, because mean scores were so different between cisgender and transgender women, scores were separated to create even smaller sample sizes. However, it should be reminded that the overall purpose of the research described in this paper was to assess acceptability and feasibility of UPLIFT for a new target group. Therefore, though outcome measures are informative, they were expected to have limitations. Findings in this study will help to inform evaluation in larger groups if cisgender AAWLWHA.
Another limitation in the current study was related to the phone delivery of the intervention. While women rated this as one of the favorable components of the intervention, the method was not completely convenient for everyone. Due to limited funds for the dissertation research described here, a free phone conferencing system was utilized. Shortly after beginning the 8-week UPLIFT group sessions, the researchers learned that two of the women who dropped out did so because they had local phone service that did not allow them to dial in to a long-distance number. In the future, funding will be sought to pay for a toll-free number accessible to multiple cell phone providers. In a planned mindfulness training phone study, the researchers highlight the access that low-income patients who qualify based on poverty guidelines can be provided a cell phone, highlighting the ease of delivering such training by phone (Salmoirago-Blotcher et al.). However, it should be noted that researchers should be careful about the selection of phone lines used for this purpose. They may not all be accessible depending on what conference call account is obtained.

Another limitation related to the ability to participate in groups. One participant who missed a session due to illness asked if there was the possibility of participating in a make-up session. Though this was not possible for these open trials given that it requires group participation, this is a consideration for the future. In a research context, some participants may want to make up sessions as not to lose out on incentives; however, from a dose-response perspective, perhaps make-up sessions that will allow participants to be exposed to the content for that week is something key to consider.

Finally, during Session 8, women expressed interest in remaining in touch with women beyond UPLIFT. Women gave ideas in their final sessions about potentially meeting up to have a “reunion”. This request seems to be related to an overall theme of
wanting to have discussion. “Group discussions” were one of the two highest rated components of the UPLIFT intervention. Additionally, cisgender women had a considerable increase in perceived availability of social support following UPLIFT with a large effect size potentially attesting to the impact of UPLIFT in this area. Perhaps in future iterations of UPLIFT for this population, the last session or one thereafter should include an optional meet-up amongst participants that might sustain changes in social support, and consequently, positively impact medication and care adherence, as well as satisfaction and quality of life.
### Table 5.1. Demographic Characteristics of Open Trial Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n=15</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender Identity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cisgender Woman</td>
<td>8</td>
<td>53.3%</td>
</tr>
<tr>
<td>Transgender Woman</td>
<td>7</td>
<td>46.6%</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>12</td>
<td>80.0%</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>2</td>
<td>13.3%</td>
</tr>
<tr>
<td>Hispanic/Latinx</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td><strong>Age in years (mean = 50.1)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>30-39</td>
<td>2</td>
<td>13.3%</td>
</tr>
<tr>
<td>40-49</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>50-59</td>
<td>4</td>
<td>26.6%</td>
</tr>
<tr>
<td>60-65</td>
<td>2</td>
<td>13.3%</td>
</tr>
<tr>
<td>65+</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9th grade or lower</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td>10th grade</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td>11th grade</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td>High school or GED</td>
<td>7</td>
<td>46.6%</td>
</tr>
<tr>
<td>Some college</td>
<td>4</td>
<td>26.6%</td>
</tr>
<tr>
<td>Graduated college</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td>Some graduate or professional school</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Completed graduate or professional school</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$0-$4,999</td>
<td>1</td>
<td>6.66%</td>
</tr>
<tr>
<td>$5,000-$9,999</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>$10,000-$14,999</td>
<td>4</td>
<td>26.6%</td>
</tr>
<tr>
<td>$15,000-$19,999</td>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>$20,000-$24,999</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>$25,000-$34,999</td>
<td>1</td>
<td>6.66%</td>
</tr>
<tr>
<td>$35,000-$39,999</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>$50,000-$74,999</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Relationship Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>8</td>
<td>53.3%</td>
</tr>
<tr>
<td>Not married, but living with a partner</td>
<td>3</td>
<td>20.0%</td>
</tr>
<tr>
<td>Married</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>4</td>
<td>26.6%</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Years since Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>5-10</td>
<td>2</td>
<td>13.3%</td>
</tr>
<tr>
<td>10-15</td>
<td>2</td>
<td>13.3%</td>
</tr>
<tr>
<td>15-20</td>
<td>4</td>
<td>26.6%</td>
</tr>
<tr>
<td>20+</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>Not reported</td>
<td>1</td>
<td>6.6%</td>
</tr>
</tbody>
</table>
Table 5.2. Open Trial Participants-Patient Health Questionnaire-9 (PHQ-9) Scores

<table>
<thead>
<tr>
<th>PHQ-9</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8.40</td>
<td>3.41</td>
<td>5-14</td>
</tr>
<tr>
<td>Session 1: Noticing Thoughts</td>
<td>Teaching: Noticing Thoughts</td>
<td>Enjoyed &quot;sharing&quot; with one another</td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td>----------------------------</td>
<td>-----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Group Activity: Identifying the Thought</td>
<td>Learning about mood, thoughts, and situations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skill Building: Introduction of Noticing Thoughts and Mood</td>
<td>Warmth felt from facilitators and other ladies on the line</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On Your Own: Thought and Feeling Record</td>
<td>Difficulty with background noise</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Call quality wasn't clear</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Had to use Google Voice to call in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 2: Checking and Changing Thoughts</td>
<td>Teaching: Checking and Changing Thoughts</td>
<td>When &quot;overgeneralizing&quot;, helps to learn to stay in the moment</td>
<td></td>
</tr>
<tr>
<td>Group Exercise: Checking and Changing Thoughts</td>
<td>Helped to rethink the way we view things, positive or negative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skill Building: &quot;ArMed Against Distress&quot;</td>
<td>Helped to learn different coping skills related to how we think</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On Your Own: Noticing and Changing</td>
<td>Call quality; noisy with so many women</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 3: Coping and Relaxing</td>
<td>Group Exercise: The &quot;What-Ifs&quot; of HIV/AIDS</td>
<td>Enjoyed the meditation exercise</td>
<td></td>
</tr>
<tr>
<td>Teaching: Coping and Relaxing</td>
<td>Learning how to relax &quot;was a blessing&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skill Building: Body Scan and Relaxing Muscles In Order</td>
<td>More people talked/participated for this session</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion: -experiences with relaxation techniques</td>
<td>People still not muting phone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review &amp; On Your Own:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 4: Attention and Mindfulness</td>
<td>Teaching: Attention and Mindfulness</td>
<td>Walking meditation helped to clear the mind</td>
<td></td>
</tr>
<tr>
<td>Group Exercise: Shell Exercise</td>
<td>Liked the walking meditation because enjoys nature and helps to keep a healthy body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion: Shell Exercise</td>
<td>Will use walking meditation carefully on the treadmill at the gym</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skill Building: Mindfulness of a Routine Activity</td>
<td>Loved how the shell exercise made you &quot;think about the small things in life that we don’t pay much attention to&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review &amp; On Your Own:</td>
<td>Liked comparing two exercises making this session more diverse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wishes groups were bigger or more group participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 5: The Present as a Calm Place</td>
<td>Teaching: The Present as a Calm Place</td>
<td>Loved learning to focus on the present, not the past or the future</td>
<td></td>
</tr>
<tr>
<td>Group Exercise/Skill Building: 3-Minute Breathing Space &amp; Seeing and Hearing Exercise</td>
<td>Enjoyed the poem, as well as music and meditation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion: Seeing and Hearing Exercise</td>
<td>Noise lessened, and call has improved</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review &amp; On Your Own:</td>
<td>Wants to become an expert at these skills to improve getting along better with self and others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 6: Thoughts as Changeable, Thoughts as Not Fixed</td>
<td>Teaching: Thoughts as Changeable, Thoughts as Not Fixed</td>
<td>Teaches how to work on problems with your thoughts</td>
<td></td>
</tr>
<tr>
<td>Group Exercise: Mindfulness of Sounds and Thoughts</td>
<td>Teaches how to focus on thoughts that can make life better</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion: Problem Solving</td>
<td>Relaxation and breathing exercise was nice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review &amp; On Your Own:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 7: Focus on Pleasure &amp; The Importance of Rewards</td>
<td>Teaching: Focus on Pleasure &amp; The Importance of Rewards</td>
<td>Bible verse reference related to getting rid of negative thoughts and going back to a pleasurable time or place</td>
<td></td>
</tr>
<tr>
<td>Group Exercise: Guided meditation with a Focus on Pleasure</td>
<td>Participation was a little low this session</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion: Meditation</td>
<td>Session went by really fast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review &amp; On Your Own:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 8: Preventing Lapses &amp; Giving Thanks</td>
<td>Teaching: Preventing Lapses into Depressed Mood: When Life Gets To Be Too Much</td>
<td>Being able to reflect on all 8 sessions and give tribute to everyone was great</td>
<td></td>
</tr>
<tr>
<td>Group Exercise: Prevention Action Plan</td>
<td>&quot;Have healed in certain areas of life because of Project UPLIFT&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Really appreciate learning these breathing skills</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5.4. UPLIFT Client Satisfaction Questionnaire, Open Trial Participants

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3 (20%)</th>
<th>4 (80%)</th>
<th>Item Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you rate the quality of Project UPLIFT?</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>12</td>
<td>3.8</td>
</tr>
<tr>
<td>Did you get what you wanted from Project UPLIFT?</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>14</td>
<td>3.9</td>
</tr>
<tr>
<td>To what extent has UPLIFT met your needs?</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>10</td>
<td>3.7</td>
</tr>
<tr>
<td>If a friend was in need of similar help. Would you recommend UPLIFT to him or her?</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>14</td>
<td>3.9</td>
</tr>
<tr>
<td>How satisfied are you with the amount of help you have received?</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>In an overall, general sense, how satisfied are you with what you have received?</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>If you were to seek help again, would you come back to Project UPLIFT?</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>4</td>
</tr>
</tbody>
</table>
Table 5.5. Outcome Evaluation from UPLIFT Open Trials with AAWLWHA

<table>
<thead>
<tr>
<th>Measure</th>
<th>Cisgender (N=8)</th>
<th>Transgender (N=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-Test Mean (SD)</td>
<td>Post-test Mean (SD)</td>
</tr>
<tr>
<td>Knowledge</td>
<td>12.13 (2.23)</td>
<td>12.25 (1.28)</td>
</tr>
<tr>
<td>Skills</td>
<td>53.75 (8.83)</td>
<td>55.50 (7.93)</td>
</tr>
<tr>
<td>MAAS</td>
<td>46.5 (11.75)</td>
<td>53.75 (14.95)</td>
</tr>
<tr>
<td>BDI</td>
<td>15.50 (11.40)</td>
<td>11.38 (8.45)</td>
</tr>
<tr>
<td>BAI</td>
<td>20.50 (14.10)</td>
<td>17.50 (11.58)</td>
</tr>
<tr>
<td>PSS</td>
<td>17.75 (5.18)</td>
<td>16.13 (9.63)</td>
</tr>
<tr>
<td>CSES</td>
<td>195.88 (46.48)</td>
<td>214.00 (26.23)</td>
</tr>
<tr>
<td>SWLS</td>
<td>22.50 (6.78)</td>
<td>24.75 (4.71)</td>
</tr>
<tr>
<td>PASS</td>
<td>28.38 (5.45)</td>
<td>32.50 (3.12)</td>
</tr>
<tr>
<td>PTSD Hypervigilance</td>
<td>3.25 (1.75)</td>
<td>3.88 (1.96)</td>
</tr>
<tr>
<td>PTSD Intrusion</td>
<td>4.75 (3.41)</td>
<td>6.75 (3.15)</td>
</tr>
<tr>
<td>PTSD Avoidance</td>
<td>3.00 (2.20)</td>
<td>3.63 (2.62)</td>
</tr>
</tbody>
</table>
CHAPTER 6  
DISCUSSION

African American women are at higher risk for HIV/AIDS than any other racial or ethnic group (CDC, 2015). Further, chronic disease populations such as those living with HIV/AIDS, are at increased risk for depression as compared to those in the general population (NIMH). To exacerbate this vulnerability even further, one theory posits that African American women with HIV/AIDS tend to be “silent” about their mental health (DeMarco & Lanier, 2014). Considering the evidenced relationships between depression and care and treatment adherence, and quality of life for PLWHA (Willie et al., 2015)-the mental health of this population should be of great concern. Addressing mental health concerns could improve disease prognosis, and quality of life for this target population.

Given the potential consequences of untreated depression in African American HIV-seropositive women, there is an urgent need for behavioral interventions for this population. Despite existing behavioral interventions for PLWHA, no known interventions are tailored for African American women and improving their mental health. This might well be because of the lack of exploratory work done in this area, and therefore, targeted interventions for this group. This research aimed to address this gap in literature and in practice by considering the use of a mindfulness-based cognitive therapy intervention, Project UPLIFT, for AAWLWHA.

The promise of mindfulness-based interventions for this population is supported by other studies that show improvements in mental health and HIV-related outcomes
for PLWHA (Gonzalez-Garcia, Ferrer, Borras, Munoz-Moreno, et al., 2013; Moskowitz et al., 2015; SeyedAlinaghi et al., 2012). Despite the success of both mindfulness-based stress reduction programs and mindfulness-based cognitive therapy programs for PLWHA, none have included samples of HIV-seropositive African American women (Yang et al., 2015). Though UPLIFT had never previously been used for this population, its success for those living with epilepsy or seizure disorder, as well as those with cystic fibrosis, it was an appropriate opportunity to consider the adaptation of the intervention for this population.

UPLIFT is an 8-week distance-delivered intervention designed by faculty at Emory University Rollins School of Public Health, to improve mental health outcomes of those living with epilepsy. For populations of persons with epilepsy or seizure disorder, UPLIFT was effective in clinical trials in improving knowledge and skills about mindfulness and cognitive behavioral techniques, as well as reducing depressive symptoms (Thompson et al., 2015). The intervention was found to be equally effective by both web and phone in a clinical trial comparing both formats (Thompson et al., 2015).

Study Aims

Considering UPLIFT for HIV-seropositive African American women was in response to its need and the potential ease of adapting an already existing evidence-based intervention. The purpose of this research, broadly, was to adapt and evaluate UPLIFT for AAWLWHA in Georgia. The specific aims of the project were as follows:

1) Adapt UPLIFT materials for AAWLWHA. Focus groups will be utilized to identify and implement appropriate modifications to
UPLIFT intervention materials. This adaptation will have a specific focus on tailoring for relevant disease specific information, and cultural acceptance and appropriateness.

a. **Utilize formative strategies to explore needed modifications to UPLIFT.** Three focus groups will be conducted with a total of 15-20 AAWLWHA to learn more about the impact of HIV diagnosis, perceptions of stigma in the community, experiences of depression, barriers to care and medication adherence, and most importantly, how UPLIFT might be best adapted for this population. Intervention content and exercises will be presented during focus groups for feedback.

b. **Conduct expert review assessment of adapted UPLIFT intervention.** Several experts including AAWLWHA in Georgia, professionals providing behavioral intervention facilitation and training for AAWLWHA, and the primary investigator who designed Project UPLIFT. These experts will be solicited for detailed feedback on the UPLIFT intervention.

2) **Conduct two open trials to evaluate adapted UPLIFT intervention.** The adapted UPLIFT intervention material will be delivered to two groups of AAWLWHA. UPLIFT groups work best to include 6 to 8 women. Evaluation data will be collected after every
session and at the end of the intervention to identify intervention components that worked well and those that might need further adaptation. Women will be asked to participate in two assessments, one prior to the start of the UPLIFT intervention sessions, and another following. Data will be collected from facilitators following each intervention weekly session to assess ease of facilitation and gather information on group material.

*Phase I* of the study was designated for conducting the qualitative/exploratory phase purposed for obtaining formative feedback on UPLIFT intervention. This phase consisted of three focus groups of 18 women. Focus groups lasted approximately 2 hours, and were held at two local AIDS-service organizations in Georgia where most of the women were already receiving care. During focus groups, women revealed that they found the intervention to be acceptable, with few concerns and few recommendations for modification. Among few concerns, two transgender women expressed their dislike of a mindfulness exercise that included a pebble, reminiscent of the classic “raisin exercise” developed by Jon Kabat-Zinn in one of the first MBCT developed programs. The women believed that the pebble (mostly white in color) was a reminder of their crack cocaine addiction for which both had recently recovered. One woman shared the disdain her partner would have if she were to bring the pebble home, as they had been offered the option of bringing UPLIFT materials home after the focus groups. Another concern by one of the same women was with the full Body Scan exercise. The woman shared that the exercise was “boring...and too detailed”. She seemed to prefer the 3-
minute Breathing Exercise that was facilitated later in the focus group because it was less time-consuming and less detailed in its reference to scanning body parts.

In addition to asking for feedback on UPLIFT content, focus groups solicited assistance on the best ways to reach women for an open trial of the intervention, how to best conduct intervention sessions, and incentivizing as contacting women throughout UPLIFT if enrolled.

Women suggested that women be approached via posting flyers throughout the organization just as the flyers were posted to reach women for focus groups. It was also suggested that specific staff at the ASO was contacted about the impending UPLIFT open trials, and asked to assist with recruitment. Regarding the format of UPLIFT sessions, women were asked whether they thought it would be best to conduct UPLIFT sessions in person or by phone (as previously delivered for PWE). The opinions regarding format were somewhat mixed. A couple women initially stated that it would be best to have the group in person, but then posed questions later about how one could maintain anonymity if one participated in-person. The women then began a conversation regarding the small HIV community in the local Atlanta area and how disclosure of status and confidentiality of that status would be a concern. The women later retracted suggesting that maybe the phone delivery would be best considering those concerns. Other women very clearly stated that phone facilitation would likely be best because of convenience, anonymity, and access due to lack of transportation. One woman shared that she’d likely participate if by phone because it reminded her of her weekly prayer line/meditation calls for her church. In discussing incentives, focus group participants agreed that gift cards would work best for open trial participation.
compensation. Women also agreed that they would be okay with receiving UPLIFT materials and incentive mailings at their home address.

One additional segment of Phase 1 included expert review of UPLIFT materials. Expert reviewers were provided the intervention materials, and asked to spend 2 weeks conducting a thorough review and making note of what they liked, didn’t like, and would change about the materials. They were asked to notify the primary researcher at the end of the two weeks to schedule a time to meet and review their feedback. Overall, the experts all found the intervention to be acceptable with the target group in mind. The cisgender and transgender women living with HIV/AIDS both stated that they liked everything about the intervention and would change nothing. A health educator who has worked in the HIV/AIDS field and provides facilitation and training for behavioral interventions with the target group shared the most feedback as an expert. Her suggestions were to change the wording in some of the teaching content to be shorter and more direct. Additionally, she shared recommendations on very specific wording throughout the facilitator and participant manuals.

Phase II of the study was designated for conducting two open trials of the adapted UPLIFT intervention. Women were recruited and rather than randomly assigned, openly enrolled into one of two UPLIFT groups. Based on what was learned from focus groups to include differences in the psychosocial experiences of cisgender and transgender African American women, as well as observed tension between the two groups- it was decided to conduct the groups separately. Therefore, women were enrolled into one of two groups based on self-reported gender identity.

Ten women were screened, consented, and enrolled for Group A (cisgender women) and eight women were screened, consented, and enrolled for Group B
(transgender women). All 18 women completed the pre-test phone survey prior to the start of UPLIFT. As expected, a few women (2 from Group A and 1 from Group B) dropped before beginning the first UPLIFT session. The reasons for dropping were noted as two women having difficulty calling into the designated conference line because of having a phone that did not support dialing numbers outside of local area codes, and the last was noted as a loss of contact.

At the start of Session 1, there were eight women in Group A and seven women in Group B. Attendance was mostly optimal in both groups. One woman in Group B missed three sessions due to illness and reported hospitalization. Otherwise, all women completed at least 80% of UPLIFT sessions by phone. In addition to completing weekly UPLIFT calls, women were asked to call and leave feedback after and about each individual session. There were minimal complaints about UPLIFT or suggestions for change. Unfavorable comments were related to primarily call quality because of background noise, and gift card incentives. Additionally, based on a quantitative assessment of acceptability at post-test, women were highly satisfied with the UPLIFT intervention and its components.

As it relates to feasibility of the intervention, women completed a 22-item process evaluation survey as a part of the post-test phone survey. Based on those findings, women seemed to most value the group discussions during UPLIFT sessions, as well as the delivery format of using the telephone. Group B scored the process lower than Group A. Further, in feasibility ratings from the UPLIFT facilitators, Group B was scored consistently lower than Group A on engagement, understanding of material, and overall ratings of the sessions across all 8 sessions. Audio recordings of UPLIFT sessions
corroborated that there was much more difficulty keeping Group B participants focused and on task, and ascertaining whether they were fully engaged with the material.

In outcome evaluation, cisgender women improved across all outcomes in the expected direction with reduced symptoms of stress, anxiety, and depression- and an increase in knowledge and skills, mindful attention and awareness, and coping self-efficacy, satisfaction with life, and perceived availability of social support. In contrast, transgender women had changes in six measures from pre-test to post-test in the opposite direction as hypothesized- knowledge, anxiety, mindful attention and awareness, coping self-efficacy, satisfaction with life, and perceived availability of social support.

**Limitations**

As with all research, this study had several limitations. Firstly, the study’s focus was on adaptation and process evaluation of an evidence-based intervention being assessed for its utility with a new population. Given that goal and how formative this work is, sample sizes were small and generalizability of findings is extremely limited. The sample is only representative of a small group of women living with HIV/AIDS in the state of Georgia. These findings should in no way be applied to people who may be culturally, demographically, and geographically unique as compared to the women who participated.

Women were initially recruited from a specific Georgia ASO which limited the pool of potential participants, though this seemed to be the safest option from a mental health perspective. However, this did add to the homogeneity of the sampling pool for participation. Additionally, screening data collected included information about where
women heard about the study. Women receiving care at other ASOs, attending events in the local Atlanta area, as well as women on an online forum contacted the primary researcher regarding interest in the study.

Feedback on modifications that could be made to the UPLIFT intervention to make it as culturally appropriate and sensitive as need be for its maximum potential effectiveness was limited to the space and time of the research activities described in this dissertation. Focus groups, while useful in learning what worked and didn’t work, were limited to 2 hours. Many women appreciate and enjoy the discussion and support being provided. This also limits time to discuss the UPLIFT intervention content. To offset this limited time, expert review offered women, two from this target group, to spend an extended amount of time with the UPLIFT material and provide advice on needed modifications. Additionally, women were given the opportunity to give feedback every week as they were participating in the UPLIFT open trial sessions.

Incentives seemed to be a motivator for many of the women who participated in the open trials, particularly Group B. While all attempts were made to assure that the incentive for participation was not coercive, it is recognized that perhaps some women were participating mostly for a desire of receiving incentive. The incomes reported by women participating in the first phase focus groups and the second phase open trials were below 25K per year for both samples of women (with the exception of 1 participant with a higher income between 255K and 34,999), which demonstrates the potential financial burden for many of the participants.
Conclusions/Implications

Project UPLIFT appears to have great potential for improving the psychosocial functioning of AAWLWA. As the first known study to consider an MBCT intervention for improving mental health among this group, this demonstrates promise for fulfilling a gap in literature and practice for a group that is particularly vulnerable. Overall, UPLIFT was found to be both acceptable and feasible for cisgender African American women. Furthermore, African American cisgender women enrolled in open trials improved on all outcome measures of the study in the hypothesized directions. This supports the potential for assessing preliminary efficacy through a large, randomized controlled trial of UPLIFT with this group. It would be expected that an RCT as a next step would attempt reach wider and a more diverse group of women who qualified for participation. The use of the telephone for delivery makes this reach quite feasible.

Though UPLIFT was highly acceptable to transgender women, it seemed potentially less feasible as demonstrated by process data in open trials. So little is known about the mental health of African American transgender women and African American transgender women living with HIV/AIDS. It is possible that UPLIFT could use further formative work assessing changes that could be made to improve its relevance for transgender women. Beyond this, it is possible that more needs to be learned qualitatively about the psychosocial experiences of transgender women before considering UPLIFT as a way of improving mental health among this group. It would be the recommendation of the current researcher to conduct more formative research in this area before extending further research on UPLIFT for African American transgender women.
REFERENCES


Sikkema, K. J., Hansen, N. B., Tarakeshwar, N., Kochman, A., Tate, D. C., & Lee, R. S. (2004). The clinical significance of change in trauma-related symptoms following a pilot group intervention for


PROJECT UPLIFT
PAID VOLUNTEERS NEEDED FOR RESEARCH STUDY:

To talk about ‘Project UPLIFT’, a program to reduce stress and improve mood.

If you are interested or have questions, please contact Josalin at:
(770) 765-0690
or
upliftforпозwomen@gmail.com

YOU MAY BE ABLE TO PARTICIPATE IF YOU:

IDENTIFY AS AFRICAN AMERICAN OR BLACK

IDENTIFY AS A WOMAN

ARE 18 YEARS OR OLDER

HAVE BEEN DIAGNOSED BY A HEALTHCARE PROVIDER WITH HIV OR AIDS

ARE WILLING TO MEET WITH A GROUP IN-PERSON FOR 1 TO 1.5 HOUR
PROJECT UPLIFT
PAID VOLUNTEERS NEEDED FOR RESEARCH STUDY:

To take part in ‘Project UPLIFT’, a program designed to reduce stress and improve mood.

If you are eligible and take part in the program, you could be compensated up to $110 for your time.

YOU MAY BE ABLE TO PARTICIPATE IF YOU:

IDENTIFY AS AFRICAN AMERICAN OR BLACK

IDENTIFY AS A WOMAN

ARE 18 YEARS OR OLDER

HAVE BEEN DIAGNOSED BY A HEALTHCARE PROVIDER WITH HIV OR AIDS

ARE WILLING TO TAKE PART IN AN 8-WEEK PHONE GROUP PROGRAM & TAKE 2 SURVEYS

If you are interested or have questions, PLEASE CONTACT JOSALIN AT

(770) 765-0690

OR

upliftforpozwomen@gmail.com
Consent Letter
Focus Groups

Date: __________

Participant ID: __________

Dear __________,

I am a graduate student under the direction of Dr. Nathan Hansen in the Department of Health Promotion and Behavior of College of Public Health at The University of Georgia. I invite you to participate in a research study entitled Project UPLIFT for African American Women Living with HIV/AIDS. The purpose of this study is to explore the experiences of African American women living with HIV/AIDS in Georgia, and to discuss current ways of coping with stress. Additionally, I would like to know your opinions about Project UPLIFT, a program to reduce stress and improve mood.

Participation in this study requires that you: 1) identify as African American or Black, 2) Identify as a woman, 3) Are 18 years of age or older, 4) be cognitively apt, 5) Meet specific requirements for depressive symptoms, and 6) have been diagnosed by a healthcare provider with HIV or AIDS.

Your participation will involve meeting with a group of other women like you. It should only take about 1 to 1.5 hours. Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled. If you decide to withdraw from the study, the information that can be identified as yours will be kept as part of the study and may continue to be analyzed, unless you make a written request to remove, return, or destroy the information. Your decision to participate or not will have no bearing on the treatment or services that you receive from Positive Impact.

All information collected will be kept confidential unless we learn of child abuse, elder abuse, or intent to harm yourself or others. In these scenarios, we will voluntarily breach confidentiality to report this information to state officials or to obtain help to make sure that you and others are safe. The investigator will emphasize to all participants that comments made during the focus group session should be kept confidential. However, it is possible that participants may repeat comments outside of the group at some time in the future. During the group, you will be allowed to use whatever name you are most comfortable using. Otherwise, I will do my best to keep your identity private. The group will be audio-recorded to assure the accuracy of the information you provide. After the groups have ended, the group recordings will be transcribed and de-identified. Any information providing your identity will be locked in a file cabinet and destroyed after data analysis is complete. Any electronic files and information providing your identity will be stored on a password protected computer and deleted after data analysis is complete. This information will only be accessed by the primary researcher, Josalin Hunter-Jones, faculty advisor, Dr. Nathan Hansen, and research staff involved on this project. The results of the research study may be presented and/or published, but your name or any identifying information will not be used. In fact, the published results will be presented in summary form only.
Consent Letter

Individual Program Feedback

Date: __________
Participant ID: __________

I am a graduate student under the direction of Dr. Nathan Hansen in the Department of Health Promotion and Behavior of College of Public Health at The University of Georgia. The purpose of this research study is to learn if and how a program called Project UPLIFT might benefit African American women living with HIV or AIDS.

Participation in this portion of the study requires that you: 1) Identify as African American or Black, 2) Identify as a woman, 3) Are 18 years of age or older, and 4) Have been diagnosed by a healthcare provider with HIV or AIDS, or work directly with women who fit the above criteria.

Your participation will involve reviewing Project UPLIFT program materials. You will be given 1 to 2 weeks to review the materials on your own during which time you should spend about an hour of total time reviewing. After that, we will meet in-person for no more than an hour to discuss your feedback. At the in-person meeting, I will be taking notes and audio-recording to make sure I don’t miss anything.

All information collected will be kept confidential. Any information providing your identity will be locked in a file cabinet and destroyed after data analysis is complete. Findings from this research study may be presented and/or published, but your name or any identifying information will not be used. In fact, the published results will be presented in summary form only.

Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled.

You will receive $40 cash as reimbursement for your time at the completion of the in-person meeting.

If you have any questions about this research project, please feel free to call me, Josalin Hunter-Jones at 770-765-0690 or send an e-mail to upliftforpozwomen@gmail.com. Questions or concerns about your rights as a research participant should be directed to The Chairperson, University of Georgia Institutional Review Board, 609 Boyd GSRC, Athens, Georgia 30602, telephone (706) 542-3199; email address irb@uga.edu.

By providing verbal consent, you are agreeing to participate in the above described research project.

_____ Agrees to participate
_____ Does not agree to participate

Thank you for your consideration! You will receive a copy of this consent letter for your records.

Sincerely,

Page 1 of 2
Consent Letter
UPLIFT Program

Date: __________

Participant ID: __________

Dear __________,

I am a graduate student under the direction of Dr. Nathan Hansen in the Department of Health Promotion and Behavior of College of Public Health at The University of Georgia. I invite you to participate in a research study entitled Project UPLIFT for African American Women Living with HIV/AIDS. The purpose of this phase of the study is to evaluate the process of running the Project UPLIFT program with two groups of women.

Participation in this study requires that you: 1) Identify as African American or Black, 2) Identify as a woman, 3) Are 18 years of age or older, and 4) Have been diagnosed by a healthcare provider with HIV or AIDS.

Your participation in this phase of the study would involve the following: 1) a pre-test, 2) a post-test, 3) 8 weekly one hour conference call sessions (Project UPLIFT), and 4) leaving a follow-up voice recording answering 3 questions after each session. If you agree to participate, you will be enrolled in the study for approximately 10 weeks- one week in which your pre-test will be completed, 8 weeks in which you will participate in Project UPLIFT groups, and an additional week in which you will complete the post-test survey. Both surveys will be administered by phone.

Project UPLIFT is an 8-week telephone delivered program focused on teaching mindfulness and cognitive behavioral skills that reduce stress and improve mood. Each weekly call will last one hour on a conference line. The call will include between 7 and 10 other African American women living with HIV or AIDS, and residing in the state of Georgia.

Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled. Your involvement at any care agency for which you might be receiving services is unrelated to this study. Further, no medical or behavioral services will be affected by your decision to participate in this study. If you decide to withdraw from the study, the information that can be identified as yours will be kept as part of the study and may continue to be analyzed, unless you make a written request to remove, return, or destroy the information.

All information collected will be kept confidential. During the group sessions, you will be allowed to use whatever name you are most comfortable using. Otherwise, we will do our best to keep your identity private. The group sessions will be audio-recorded to assure the accuracy of the information you provide. Any information provided by your identity will be locked in a file cabinet and destroyed after data analysis is complete. Any electronic files and information provided by your identity will be stored on a password protected computer and deleted after data analysis is complete. This information will only be accessed by the primary researcher, Josalin Hunter-Jones, faculty advisor, Dr. Nathan Hansen, and research staff involved on this...
PROJECT UPLIFT

Using Practice and Learning to Increase Favorable Thoughts

Treating Depression, Negative Mood, and Anxiety

A Mindfulness-Based Cognitive Behavioral Program for Women Living with HIV/AIDS

Telephone Group Manual

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