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Hypertensive Medication Adherence in Young Adult African American Women 18-45 Years of Age

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Hypertensive Medication Adherence in Young Adult African American Women 18-45 Years of Age

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An abstract of
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Abstract
Hypertensive Medication Adherence in Young Adult African American Women 18-45 Years of Age

By Telisa A. Spikes

Background: Hypertension (HTN), a modifiable contributor of cardiovascular disease (CVD) maintains its presence as a significant public health threat in the United States and worldwide. African American (AA) women age 20 years and older have the highest prevalence of HTN compared to white women (44% vs. 28%). AAs 18-49 years are twice as likely to die from heart disease as whites and AAs aged 35-64 years are 50% more likely to have HTN compared to whites. Additionally, poor adherence and non-adherence to hypertensive medications have been strongly indicated as a primary contributor to the early onset of disparity in CVD morbidity and mortality that is experienced by AAs.

Purpose: The purpose of this dissertation was to examine blood pressure medication adherence in AA women relative to sociodemographic, clinical, cultural context, psychosocial, cognitive and behavioral processes factors.

Sample and Design: This was a cross-sectional dissertation study with prospective data collection of hypertensive AA women 18-45 years of age (N=85, mean age 39±5.4 years). Variables and measures included: sociodemographic characteristics (age, education, income, health insurance), clinical (blood pressure & comorbidities), exposure to lifetime gender and racial stressors (SSE_SRE), depressive symptoms (PHQ-8), social support (ENRICH-D), HTN illness perceptions (BIPQ), resilient coping (CDRISC-10), and medication adherence (ARMS-7). Analysis included descriptive statistics, correlations, and multiple regressions.

Results: 81% of the sample were categorized as non-adherent. SBP was the only clinical covariate associated with HTN medication adherence. None of the predictor variables, overall HTN illness perceptions composite score, resilient coping, depressive symptoms, exposure to lifetime gender and racial stressors, or social support were associated with HTN medication adherence. There were group differences, adherent vs. non-adherent, on the 'Consequence' (OR=0.78, p=.01) and 'Identity' (OR=0.76, p=.02) dimensions associated with HTN medication adherence and higher income was a significant predictor of HTN medication adherence (OR=1.80, p=0.02).

Conclusions: The findings of this study suggest that components of HTN illness beliefs and sociodemographics, specifically income, are two important contributors to medication adherence in this population. This finding demonstrates the need and importance for clinicians to have open and honest communication regarding HTN and its treatment in facilitating adherence.

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Chapter 1: Introduction

Significance of the Problem

Hypertension [HTN] is an important predisposing risk factor for the development of cardiovascular disease (CVD) and premature mortality.[1] National spending associated with HTN in the United States has increased consistently from $58.7 billion dollars in 2000-2001 to $109.1 billion dollars in 2012-2013.[2] Additionally, medical expenditures associated with HTN increased significantly for females from 2000-2001 ($1,132) to 2012-2013 ($2,096), while expenditures remained unchanged for males.[2] African American [AA] women represent the leading ethnic group of adults age 20 years and older with the highest prevalence of HTN [44%] followed by AA men [42.4%], and White men and women [30.2% & 28%], respectively.[3,4] More importantly, AA women have the highest death rates from heart disease, a complication of uncontrolled HTN.[5,6] Additionally, AAs aged 18-49 years are twice as likely to die from heart disease as Whites, and AAs aged 35-64 years are 50% more likely to have HTN compared to Whites.[7]

Poor adherence and non-adherence to hypertensive medications have been strongly indicated as a primary contributor to the early onset of disparity in CVD morbidity and mortality that is experienced by AAs.[5,8] Because AAs are diagnosed with HTN at earlier ages and incur cumulative and rapid progression of organ involvement including end stage renal disease and stroke compared to other racial groups as a result of poorly controlled HTN,[9,10] identifying the factors that influence blood pressure [BP] medication adherence in younger AAs is imperative in order to decrease the progression of poor outcomes associated with uncontrolled HTN later in the life course. This is

especially relevant for AA women, a group susceptible to various competing demands and stressors that can distract from the importance of BP medication adherence.

Adequately managing HTN can greatly reduce the morbidity and mortality associated with uncontrolled HTN,[10,11] but in order to adequately manage HTN in a high-risk population, medications must be part of the regimen, and must be taken. In addition, understanding the factors that contribute to HTN control is also warranted. What remains unclear is the knowledge of which factors facilitate positive BP medication adherence in spite of adverse social determinants for some women. Identification and examination of the barriers to BP medication adherence in AAs have been instrumental in illuminating factors that contribute to poor HTN control. However,[5,12-14] factors enhancing BP medication adherence, particularly in young and early middle age adult AA women are understudied.[15] This is an important observation given that AAs in general tend to develop HTN at earlier ages,[7,15-17] are more resistant to treatment,[16,17] face unique life stressors,[5,18,19] are considered less adherent to BP medications, especially if they are younger age [<50], [5,8,15,20] and experience early onset morbidity and mortality.[7,21] Identification of the factors that enhance BP medication adherence among this vulnerable population of women is critical.

Factors Affecting Medication Adherence

Hypertension Illness Representations

Illness representations consist of cognitive and emotional representation, lay information, external sources, and existing or previous experience with a condition or illness.[22,23] They are created and initiated by somatic sensations and deviations from normal function [ex. chest pain, headache], observation and discussion of illness in others [ex. medical diagnosis], mass media and other environmental stimuli.[24,25]

Collectively, these stimuli activate prototypes or memory structures of the individual's normal functional self, past experience with illness, and treatments and lifestyle activities generating mental representations of illness threats [beliefs surrounding illness, identity, cause, control, consequences, and duration/timeline beliefs] potential treatments and the formation of action plans.[25] Based upon an individual's illness perception, engagement in treatment and self-management behavior such as medication and lifestyle adherence can be negatively or positively influenced. Beliefs surrounding the development of HTN are believed to play an integral role in the increasing prevalence of HTN in AAs.[26-28] Researchers have found that AAs perceive HTN to be a common and unavoidable stress-related illness subject to occur at any given point during their lifetime.[27,29] In the absence of symptoms, operationalizing an asymptomatic condition presents as a challenge for patients by inhibiting the adoption of a treatment plan that is deemed to improve overall cardiovascular health.[23] This study will fill this gap by identifying illness perceptions regarding traditional BP medications in young AA women who demonstrate high and varying levels of BP medication adherence.

Resilient Coping

Resilient coping, derived from psychological resilience, is considered to be an important protective behavioral factor in sustaining health and promotion of self-management behavior; however, the relationship between resilient coping and health is not clearly understood.[30,31] Resilience, which emanates from early locus of control studies, is conceptualized as a dynamic developmental process encompassing the ability to bounce back, overcome, and achieve a positive sense of well-being despite exposure to adverse circumstances and situations.[19,30,32-34] Resilience is suggested to be a fluid attribute that has the tendency to change according to an individual's life

circumstances.[35] AAs are at an increased risk for experiencing early life stressors and adverse situations.[19,36,37] Despite subjection to early life stressors and persistent adverse exposures, many AAs actually avoid ill-health, negative well-being, and maladaptive coping behaviors to achieve a positive sense of well-being and health.[38,39] Much of the resilience literature in AAs have been centered around AA youth relative to behavioral development and functioning in the face of adversity and trauma[34,40,41] and adverse social conditions;[19,37] however, the relationship of resilient coping as a protective behavioral factor in attaining positive health behaviors in the presence of various stress exposures have not been well represented in the resilience literature.[30] In order to garner an understanding into the facilitators of BP medication adherence in young adult AA women, this study will examine the moderating effect that resilient coping has on BP medication adherence.

Exposure to Negative life Stressors

Stressors are defined as the problems, hardships, or threats that challenge the adaptive capacities of people.[42] Stressors unique to AAs have been commonly associated with adverse circumstances such as racial and gender discrimination,[43-45] residence in disadvantaged neighborhoods,[18,44,46] wage inequity,[37] and lower social status/structural disadvantage.[19,36-38,44,47] These stressors, juxtaposed to the unique stressors for AA women, including gender and role expectations in their families, neighborhood, and the work place, have been indicated as a major cause of racial health disparities.[48] AA adult women, both young and old, share a commonality in the stressors experienced; however, younger adult AA women confront more stressors associated with balancing work and family [42,49] which adds another layer of complexity to their vulnerability. These stressors are slightly different than experienced by men and definitely have an

adverse impact in AA women.[50-52] Repeated subjection to these stressors have predisposed AA women to poor health[47] and even greater self-ratings of poorer health.[44] In both middle and low SES groups, AAs have been found to experience a higher rate of exposure to stressors compared to whites[53,54] and were 2.26 times likely to be exposed to traumatic life events after controlling for important variables such as education, gender, early misconduct, and history of psychiatric disorder.[55] Weathering, a term developed by Geroniums, posits that Blacks experience early health deterioration as a result of the cumulative stressors and repeated exposures to social and economic adversity and political marginalization.[56] Consequentially, these stressors will eventually have a deleterious effect on overall health, whereby increasing vulnerability to illness and disease.[56,46] As a result of the subjugation to these stressors, AAs, specifically of a lower SES, are likely to engage in adverse health related behaviors [drinking, smoking, drug abuse, physical inactivity] to ameliorate the effects of adverse stressors[57] which compounds the health threats and appropriate management of HTN or any other illness.

Social Support

Social Support serves as a key protective factor in reducing an individual's vulnerability to the adverse effects of stress on health.[58] The positive benefits of social support networks have been widely examined across various chronic diseases and include increase in self-rated health, decreased psychological issues, and an increase in recovery time from serious injury or illness;[59] however, social support as a predictor of medication adherence in AAs has been considered an inconsistent and weak correlate.[60,61] In a qualitative study involving hypertensive AA participants, some of the study participants did not find their social network to be helpful in managing their HTN.

Some participants did not like the idea of their support system being involved in their medical care citing privacy issues.[62] In a qualitative study examining HTN among AA women 22-80 years of age residing in a rural area, authors found the social support system to be less supportive when attempting to make necessary lifestyle modifications including dietary changes and increasing physical activity levels to manage HTN.[63] This proposed study will examine the role and effect that social support has on medication adherence in conjunction with other antecedent factors of stress exposure and depressive symptoms.

Depressive Symptoms

Depression is regarded as an unrecognized cardiovascular risk factor in AA women diagnosed with HTN.[64] This is largely due to cultural coping and perceptions held from older generations of AA women that despite the presence of negative circumstances, one must endure and appear confident regardless of the challenges that may be present.[64,65] Cultural coping in AA women has been suggested as an antecedent for the development of chronic illness that eventually contributes to an early death for AAs.[66] Depression, regarded as a complex state of insight and crisis, cognitive awareness and compromised physiological functioning, often remains unrecognized by AA women and is under diagnosed by their health care provider;[64] further adding to the burden of ineffective self-management strategies of BP medication adherence and coping with HTN as a chronic illness.[51] The presence of depressive symptoms compound the risk for stroke in AA women largely due to poorly controlled BP in the context of uncontrolled HTN.[67] This study will examine the relationship between depressive symptoms and BP medication adherence, in relation to sociodemographic and clinical factors, HTN illness perceptions, and resilient coping in young AA women.

Blood Pressure Medication Adherence

Medication nonadherence is considered to be a modifiable contributor of the cardiovascular disparities between AAs and whites.[8] Poor BP medication adherence has been indicated as a significant risk factor of inadequate BP control in AAs.[68] Currently, there is no gold standard to adequately capture and measure the prevalence of medication adherence; thus the true rate is unknown.[69] Despite this imperfection, the odds of nonadherence to BP medications in AAs have been reported to range from 80% to 330%.[26] The rates of HTN control based on JNC-7 recommendations were also the lowest in Blacks (36.9%) and Hispanics (31.2%) compared to Whites (42.9%).[70]

Purpose of the Study

Poor cardiovascular outcomes and early mortality are direct clinical implications of inconsistent practices of BP medication adherence among this vulnerable group. Concentrating on the effects of HTN illness perceptions and resilient coping on an important behavioral risk factor, BP medication adherence, is a crucial step to understand how these factors interact and relate to BP taking behavior. The premise of this study is that greater illness perceptions will directly affect coping behavior, resilient coping, thereby facilitating BP medication adherence within the context of adverse socioeconomic, clinical, and psychosocial factors. The study will examine BP medication adherence in AA women in relation to sociodemographic [age, education, income, health insurance], clinical [BP level & comorbidities], cultural context [exposure to stressors] psychosocial [depression, and social support] and cognitive and behavioral process [HTN illness perceptions and resilient coping] factors. This study will be guided

by a model derived from the Common Sense Model of Illness Representation (CSM)[23,25] and stress and coping theories.[71,72] The proposed study will be a sub-study of a larger community heart health project [*10,000 Women Hypertension Heart Screening*]. The purpose of the parent study is to screen 10,000 AA women over a 5-year period for HTN and cardiovascular disease risk factors while, providing health education and follow-up care based upon health needs. The parent study will screen women at various locations throughout the city occurring on a bi-monthly schedule in an effort to screen 2500 women annually. The dissertation study includes a proposed sample of AA women (n=85) 18-45 years of age, currently diagnosed with HTN, and prescribed a BP medication by their medical provider. The specific aims (A) and hypotheses (H) to be addressed are:

Specific A1: Examine the effect that exposures to contextualized racial and gendered stressors, social support, and depressive symptoms have on HTN illness perceptions, resilient coping, and BP medication adherence.

H1a: Decreased exposure to adverse stressors, increased social support, and fewer depressive symptoms are associated with greater HTN illness perceptions, greater resilient coping, and increased BP medication adherence.

Specific A2: Examine the effects that HTN illness perceptions and resilient coping have on BP medication adherence in hypertensive AA women while controlling for sociodemographic and clinical factors.

H2a: Greater HTN illness perceptions are associated with increased BP medication adherence controlling for sociodemographic and clinical factors.

H2b: Greater HTN illness perceptions are associated with both increased resilient coping and BP medication adherence.

H2c: Greater resilient coping is associated with increased BP medication adherence.

Exploratory Aim: Explore the relationship of resilient coping as a potential moderator of high or low adverse stress exposure and its effect on BP medication adherence controlling for depressive symptoms.

Theoretical Framework

The framework used to guide this study is adapted from the Common Sense Model [CSM] of illness representation and Stress and Coping theory. The framework [**see figure 1.1**] will be used as a guide to examine the relationships among, psychosocial factors [depressive symptoms, racial & gendered stressors, social support], HTN illness perceptions, resilient coping, and BP medication adherence. The model and hypothesis are further described in Chapter 2. The CSM model proposes that individuals create mental representations of their illness based upon concrete and abstract sources of information in order to make sense of and manage their diagnosis.[23] Further, these mental illness representations influence how individuals will cope with the health threat that will further influence the health behavior. If individuals perceive their diagnosis of HTN as a long-term condition that has serious consequences if not properly treated, there is a greater likelihood that the benefit of taking prescribed medications will outweigh the perceived risk, thus limiting concerns of potential medication side effects. Mental representations are managed via coping strategies.[23] The presence of depressive symptoms can negatively affect coping strategies by perpetuating poor medication adherence and ultimately, uncontrolled BP. Denial, avoidance, and problem-focused coping strategies have been examined for their impact on health outcomes;[22,23] however, resilient coping has not been tested as a coping strategy of this model nor among hypertensive AA women. Resilient coping is believed to have a protective effect that

results in positive adaptive outcomes in situations of risk and adversity, especially in AAs; a minority group that is at greater risk for experiencing psychological distress associated with gender and racial discrimination.[19]

Research Design and Methods

The proposed study will be a sub-study of a larger community heart health project [*10,000 Women Hypertension Heart Screening*]. The purpose of the parent study is to screen 10,000 AA women over a 5-year period for HTN and cardiovascular disease risk factors while, providing health education and follow-up care based upon health needs. The parent study will screen women at various locations throughout the city occurring on a bi-monthly schedule in an effort to screen 2500 women annually. The parent study will document and provide the following measurements to the participants: BP, cholesterol, height/weight/body mass index, cardiovascular risk assessment, and recommended follow-up. Registered nurses and clinical nursing assistants trained in the study protocol will perform all BP measurements and blood sample collections for cholesterol test. Prior to the collection of any study data and after obtaining study consent, a demographic intake form is administered to document race, medical health history, insurance status, and income. At the completion of the screening, all participants will receive "Heart Health Education" counseling. Participants with a systolic [SBP] greater than 140/90 [or greater than 130/90 if diabetic or chronic kidney disease] will receive a 6-week follow-up phone call. The proposed sub-study ***Hypertensive Medication Adherence in Young African American Women***, will be embedded efficiently into the larger study's infrastructure as an observational cross-sectional study. For the purpose of the sub-study, "*Younger*

women" are defined as those who are 18-45 years of age since most studies have been conducted on older women. Clinic Recruitment: Prospective study recruitment will also be done on-site at the clinic locations. Prior to completion of their clinic visit, women identified as meeting the study's inclusion criteria (age 18-45 years, diagnosis of hypertension, and not pregnant) and referred by their medical provider, will be given an overview of the dissertation study entitled '*Hypertensive Medication Adherence in Young African American Women'* in a designated and private area, where the PI will discuss the study's purpose, background, and data (intake form, questionnaires, blood pressure, and cholesterol if not obtained within the last year) that will need to be collected. Once this information is provided, the PI will ask the participant if they have any questions or concerns. If there are no concerns or further questions, the participant will be asked if they would like to enroll into the study. If the response is "Yes", the participant will be given a study consent by the PI at which time, the PI will explain the informed consent process and end with time for the participant to ask any additional questions prior to obtaining a signature. If the participant decides not to enroll into the study, all study discussion will be terminated immediately.

Setting and Sample Recruitment: The sub-study will recruit n=85 AA women 18-45 years of age who have a history of HTN and are currently prescribed at least one BP medication from the following: 10,000 women health screenings, Emory University outpatient cardiology clinics, and Grady Memorial Hospital (healthcare facility that serves a primarily indigent patient population) outpatient cardiology clinics. Participant recruitment from the health screenings for the parent study will be conducted in collaboration with community businesses and organizations such as malls, churches, courthouses, professional membership organizations, schools and health care entities

across the metropolitan Atlanta area. Given the diversity of the metropolitan Atlanta area, the screening sites were selected to allow for a diverse representation of AA women based upon sociodemographic profiles [income, insurance status, and employment status], providing sufficient variation in the psychosocial factors and health behavior of interest. Inclusion criteria: Inclusion criteria of the proposed sub-study will be the same as the parent study with addition of a targeted age of 18-45 years, and having received a prescription for at least one BP lowering medication for BP control from a medical provider. Setting the focus on a designated age group will allow for the examination of concepts and phenomena relatively understudied and unexplored among a homogenous racial sample. Exclusion criteria: non-English speaking, severe learning or cognitive disabilities, and pregnant women.

Study Protocol and Measures

Data collection for all surveys will occur at one time point. Demographic data will be collected and added to the dissertation study intake form and completed by the participant or PI. 2 Blood pressures will be taken, averaged, and recorded onto the intake form prior to the completion of any study questionnaires. Cholesterol measurements will be obtained using the Cardiochek cholesterol point of care testing to analyze blood sample by sticking the tip of the participants' finger. Once the sample has been obtained, the cholestech cartridge will be discarded in a red sharps container and properly discarded with biohazard waste. All questionnaires will be completed using an I-pad where completed data will be safely and securely stored in the HIPPA compliant REDCAP database. In the event of IT issues such as Internet connectivity issues or extremely slow or decreased connection speeds inhibiting the forms to properly reload and save, paper copies of the questionnaires will be made available for the participants

to complete. At the completion, all responses will be entered into REDCap by the study PI. Approximately 30 minutes is anticipated to complete the intake form and study questionnaires.

Data collection: Table 1 describes the study variables and corresponding instruments that were collected in the dissertation study. Data collection for all surveys will occur at one time point.

Table 1.1. Overview of Variables & Measures for HTN and Young AA women

Concept	Measurement Title	Description	Characteristics
Demographics and Clinical information	Participant intake form	Self report	Age, income, education, insurance status, marital status, number of comorbidities,
Resilience coping	Connor Davidson Resilience Scale [CD-RISC 10]	10-items, used to assess an individual's level of resiliency in the face of adversity. Higher scores represent greater resilience.	Total scores range of 0-40.[73] Cronbach's alpha value of .85.[33] The scale has been tested in a wide variety of populations & ethnic groups ranging from children to adults & AAs.
HTN Illness Perception	Brief Illness Perception Questionnaire [IPQ]	9-items, 5-components that assess illness representation-identity, consequences, timeline, control/cure, and cause.[74]	The Cronbach's alpha value ranges between .87-.90 and has been tested in the AA population in various studies.[74]
Adverse exposure to Contextualized Racial and Gendered Stressors	Lifetime Racial and Gender Discrimination Experiences.	22-item measure that assesses sexist and gender discrimination experiences in the lives of women.[50]	Total Cronbach alpha value for the instrument is .88. The schedule of racist events has a Cronbach's alpha value of .92 and schedule of sexist events Cronbach's alpha value is .84.[50] Both scales have been validated in the AA population.

Social Support	Enhancing Recovery in Coronary Heart Disease	7-item self-report survey assessing four defining attributes of social support: emotional, instrumental, informational, and appraisal.[75]	Cronbach's alpha is 0.88 and the scale has been tested extensively in a variety of cardiac patient populations.[75]
Medication Adherence	Adherence to Refills and Medications Scale [ARMS]	7-items total, 2-subscales representing taking medications and refilling medications,[76,77]	Scores range from 7-28 with higher scores indicative of better adherence and scores less than 28 indicative of some degree of nonadherence.[76] Cronbach's alpha range from 0.81-0.82, validated in AA population
Depressive Symptoms	Patient Health Questionnaire [PHQ-8]	8-item screening and diagnostic tool for depressive symptoms.[78]	Scores range from 0-3 per question with a maximum score of 27. Validated instrument with a Cronbach's alpha of 0.89, sensitivity range of 84% and specificity of 72%.[78]
Blood Pressure	Systolic and diastolic Blood Pressure	Averaged systolic and diastolic BP will be categorized as **high** <u>without diabetes</u> (>140/90) & <u>with diabetes</u> (>130/90) or <u>normal</u> (<120/80) based on Measure of BP readings based upon JNC8 guidelines.[79]	2 BP readings will be taken with the participant sitting quietly for 5-mins prior to any BP measurements. The two readings will be averaged. Alternate size cuffs will be available to ensure that the proper cuff size is obtained to prevent an erroneous BP reading.

Data Analysis

Data analysis for this proposed cross-sectional study will be conducted utilizing STATA statistical software version 13.0 with alpha set at 0.05. Initial data analysis will include descriptive statistics, examination of data for normality distribution, skewness, outliers, and missing data to determine if assumptions for statistical tests have been met. Preliminary analysis will be conducted utilizing bivariate correlations, and linear regression. Specifically, age, education, income, health insurance, BP level, and number of comorbidities, will be correlated and examined for strength and significance of the relationships with scores from the CD-RISC10, Brief IPQ-9, PHQ-8, ENRICH-D, and ARMS-7. Identification of covariates and potential for multicollinearity in subsequent analysis will be assessed. Analysis of data for the specific aims will proceed as follows: **Specific Aim 1:** Examine the effect that exposures to contextualized racial and gendered stressors, social support, and depressive symptoms have on HTN illness perceptions, resilient coping, and BP medication adherence. *Approach*: For H1a, initial examination of stress exposure, social support, and depressive symptoms will be analyzed to identify which variables are significantly associated with BP medication adherence (ARMS score). Stress exposure, social support, and depressive symptoms will be entered into the model using multivariate linear regression [MLR] as a predictor of medication adherence [ARMS scores]. Interpretation of the data will hinge on the significance and the hypothesized direction of the relationships. Utilizing sequential regression blocks and stepwise variable selection methods within blocks, variables will be entered into the model and optimally selected. **Specific Aim 2:** Examine the effects that HTN illness perceptions and resilient coping have on BP medication adherence in hypertensive AA women while controlling for sociodemographic and clinical factors.

Approach: Initial bivariate relationships among HTN illness perceptions, resilient coping, sociodemographic, and clinical factors will be analyzed to identify which variables are significantly associated with BP medication adherence. For H2a, HTN illness perceptions will be entered into the model using simple linear regression [SLR] to predict BP medication adherence. For H2b, HTN illness perceptions and resilient coping will be analyzed using [MLR] as predictors of BP medication adherence. For H2c, resilient coping will be entered into the model using [SLR] to predict BP medication adherence. Variables will be analyzed for multicollinearity prior to further statistical testing. **Exploratory Aim 3:** Explore the relationship of resilient coping as a potential moderator of high or low adverse stress exposure and its effect on BP medication adherence controlling for depressive symptoms. *Approach:* To test if resilient coping moderates the relationship of BP medication adherence, an interaction effect will be tested between the predictor variable, stress exposure, and the moderating variable, resilient coping, to examine if moderation has occurred. Stress exposure and HTN illness perceptions will be entered as predictor variables separately into the model to examine and assess for differences in resilient coping scores (CD-RISC 10). A simple slopes analysis will be done utilizing regression techniques for the predictor, outcome [BP medication adherence], and moderator [resilient coping] variables. Controlling for sociodemographics and clinical factors covariates, depressive symptoms will also be tested as a confounder and controlled for appropriately.

Protection of Human Subjects

This Human Subjects Research falls under Exemption 2 as the participants involved in the *"Hypertensive Medication Adherence in Young African American Women"* study will be restricted to a one-time face to face meeting for completion of

questionnaires relating to the concepts of interest (**Illness Representations**, **Depressive symptoms**, **Negative stressors**, **Social Support**, **Resilient Coping**, and **Medication adherence**). Participants in the *Hypertensive Medication Adherence in Young African American Women Study* will be restricted to African American women 18-45 years of age who are currently diagnosed with Hypertension and are currently prescribed and/or taking a blood pressure medication(s). The 10,000 women community health screening initiative will be the primary recruiting source while the Emory and Grady cardiology outpatient clinics will be the secondary recruitment source for the target population. The clinical director of the 10,000 women community health screening initiative, Dr. Gina Lundberg, serves as the PI of the 10,000 women FAME study in addition to her role as Director of the Emory Women's Cardiology program. Past participants of 10,000 Women heart screenings who have consented to be contacted for future studies will be invited to participate. These individuals will be an important source for the recruitment pool of the *Hypertensive Medication Adherence in Young African American Women Study*. Recruitment & Informed Consent: Following an initial start-up period for IRB approval, ordering supplies, and obtaining a partial HIPAA waiver from Emory University's IRB, active recruitment for the study design will begin. Participants will be recruited into the sub-study upon entry into the parent study (10,000 women) by asking of the participant the following study eligibility questions: "Do you have a current diagnosis of Hypertension?" "Are you currently taking medication to treat your blood pressure?" "Were you born in the United States?" "Are you between the ages of 18-45 years?" "Are you pregnant?" If they meet study eligibility upon the quick screen, they will be given information about the study, time to ask questions, and if a potential participant decides to enroll, they will be given a study

consent to review and sign. Once they return the consent, they will be given the option to complete the study questionnaires on-site if time permits upon completion of the parent study screenings. If they choose to reschedule to another date/time/location, the applicant [**T. Spikes**] will coordinate a date/time/location that is mutually agreed upon by both parties. If participants wish to complete the parent study screening prior to completion of the sub-study questionnaires, they will receive a red heart sticker so that upon completion of the parent study screening, the health practitioner will assist them to the sub-study PI [T. Spikes] for completion of study questionnaires. Designated locations outside of the screening event will be places where participant privacy and confidentiality will be fostered and will include the Emory University Nell Hodgson Woodruff School of Nursing or a mutually agreeable area such as a public library. Prescreened participants from the 10K women community health screening who agreed to be contacted on the consent form will be contacted by telephone and provided information about the *Hypertensive Medication Adherence in Young African American Women Study*. The applicant [**T. Spikes**] will discuss the study with interested individuals and will ask potential participants the following study eligibility questions: "Do they have a current diagnosis of Hypertension?" "Are you currently taking medication to treat your blood pressure?" "Were you born in the United States?" "Are you between the ages of 18-45?" "And are you pregnant?" If they meet study eligibility, scheduling a date/time/and location to obtain study consent and completion of study questionnaires will be scheduled. Participants will be assured about their confidentiality and their right to refuse to answer or drop out of the study at any time. All potential participants will be required to sign and date the informed consent prior to beginning any study related procedures. All patient records including the consent forms will be

stored in a locked file cabinet in the research office and will be accessible only to the applicant. All data maintained in the computerized database will be accessible only with a login and protected, encrypted password. Study data will be de-identified using a unique subject identification number with no identifying information recorded on the data collection forms. Outpatient cardiology clinics: Informed consent of the women recruited from the outpatient cardiology clinics will be done prior to completion of their clinic visit. Women identified as meeting the study's inclusion criteria (age 18-45, diagnosis of hypertension, and not pregnant) by their provider, will be given an overview of the dissertation study entitled '*Hypertensive Medication Adherence in Young African American Women'* in a designated and private area, where the PI will discuss the study's purpose, background, and data (intake form, questionnaires, blood pressure, and cholesterol if not obtained within the last year) that will need to be collected. Once this information is provided, the PI will ask the participant if they have any questions or concerns. If there are no concerns or further questions, the participant will be asked if they would like to enroll into the study. If the response is "Yes", the participant will be given a study consent by the PI at which time, the PI will explain the informed consent process and end with time for the participant to ask any additional questions prior to obtaining a signature. If the participant decides not to enroll into the study, all study discussion will be terminated immediately.

Protection against risks: The potential risks in this study include disclosure of confidential information, possible emotional distress in completing questionnaires, and discovery of high BP levels. In order to maintain confidentiality, participant identification numbers will be assigned to ensure that all data is de-identified. The

master list that will connect the codes to identifying information will be secured in the research project office. Additionally, all data will be stored in a REDCAP HIPAA compliant system that allows for tagging of identifiers and permission to view provided to selected individuals only on the project team. All patient records will be kept in a locked file cabinet in the research office and will be accessible only to the PI and mentors with a login and protected password. Research project computers are in a locked project office. To reduce anxiety and emotional responses to the questionnaires, we will address these concerns as part of the sessions. In the rare event that participants experience emotional distress, they will be referred to Dr. Lundberg if needed for further assessment and treatment as appropriate for the situation. The total scores for both the PHQ-8 & Lifetime racial and gender discrimination experiences scale will be reviewed immediately upon receipt of the forms from participants. If the PHQ-8 reveal that participants are experiencing significant depressive symptoms [≥10], they will be contacted and counseled about the finding and asked to contact their healthcare provider. If acceptable, the data will be shared with their provider, and the patient may be referred to the Emory Healthcare Resident Psychiatry Services for further evaluation or treatment for depressive symptoms. However there are no additional funds to cover this service. In the Emory Health System and greater Atlanta community, there are several mental health services available for low or sliding scale fees. It is important to note that the PHQ-8 does not confer a diagnosis of clinical depression but is a useful screening tool for those needing further assessment. Regarding BP levels, the primary study protocol using the 2013 AHA/ACC recommendations will be used. If the BP is >140/90 but < 159/90, they will be counseled that their BP is in a range considered of concern and that they should get it rechecked within two weeks, and notify their

primary care provider if the top number is greater than 140 and the bottom number is greater than 90. If BP ≥ 160-179 mmHg- they will need provider follow up as soon as possible. If SBP ≥ 180, the participant will be referred to a cardiologist or advanced medical provider on site for assessment to determine if they need immediate medical attention.

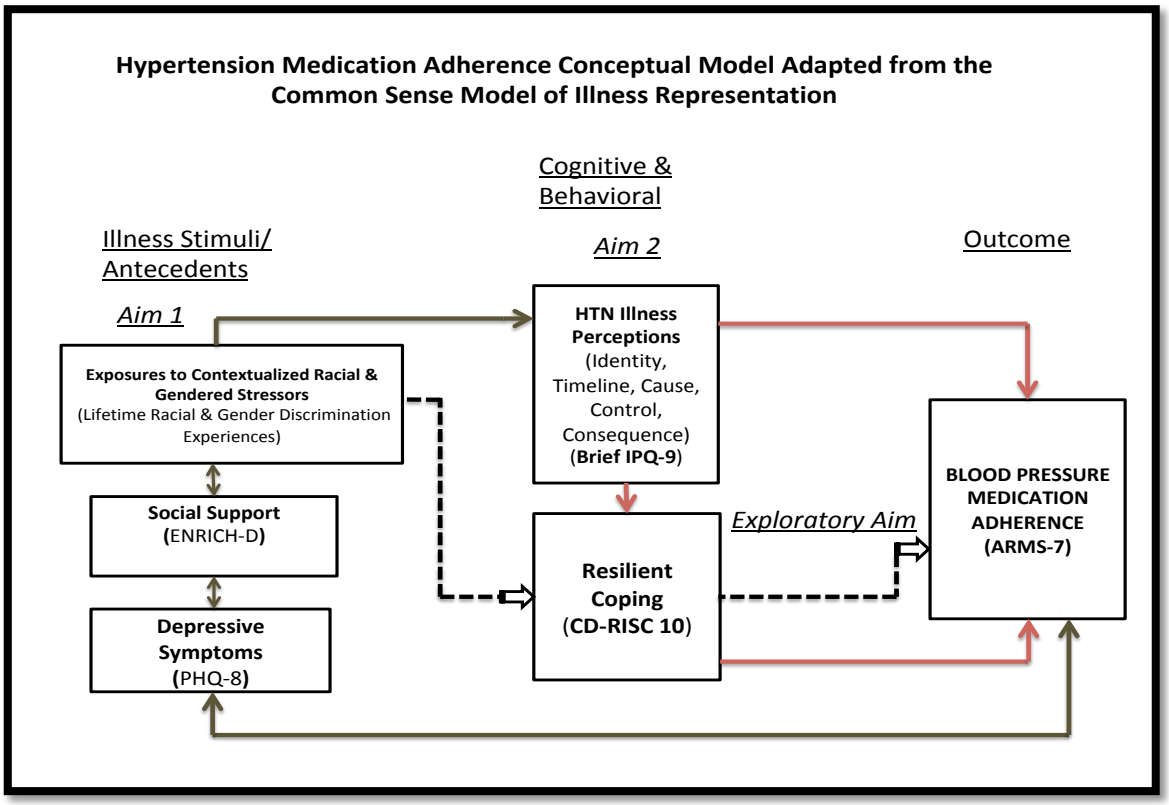
Confidentiality: To decrease the risk of breach in confidentiality and ensure the protection of participants privacy during the course of their participation in the study, a designated private location will be chosen for the confidential and private interaction between the participant and the PI where the PI can ask questions and have unlimited exchange and discussion of the study content free of judgment. Plans to establish and maintain confidentiality of the participant's identity will involve de-identifying data that includes the participants name to replace with a study ID number. Identifiers including name and date of birth will be destroyed at the end of the data collection stage once all identifiers have been replaced with a study ID number and checked for completion.

Innovation of the Proposed Study

If the aims of this study are achieved, these results will significantly add to the body of knowledge surrounding HTN illness perceptions and BP medication adherence. The study will further explain the decision-making and information processing of therapeutic interventions that are predominantly derived from beliefs associated with HTN and its treatment. The results will explicate the differences and contributing factors between AA women that have a higher degree of adherence versus those with significantly lower levels of BP medication adherence. The primary goal is to inform

future targeted interventions to positively impact BP medication adherence while acknowledging the social context in which these women live, thrive, and survive. A strength of this approach is that interventions will be adapted from a homogenous racial group, which will most likely maximize the precision of a future culturally relevant intervention to produce a beneficial and desired effect.

Figure 1.1 Conceptual Model for Hypothesis testing.



Adapted from the Common Sense Model of Illness Representations [24,25]

Summary

A cross-sectional study was conducted to explore the relationships among HTN illness beliefs, resilient coping, adverse social stressors, depressive symptoms, social support, and demographic and clinical covariates in young adults hypertensive AA women. Each specific aim has been analyzed and is presented in chapters 2-4 of this dissertation. Each chapter is prepared for submission to a peer-reviewed journal as selected by the author and mentor team. An integrative summary and analysis with implications for future research is outlined in Chapter 5.

Chapter 2

Hypertensive Medication Adherence in Young Adult African American Women: A Review of the Literature

Introduction

Hypertension (HTN), a modifiable contributor of cardiovascular disease (CVD), maintains its presence as a significant public health threat in the United States and worldwide leading to unfavorable cardiovascular outcomes if not detected and controlled. CVD, a byproduct of uncontrolled HTN, remains the leading cause of death in the United States despite medical advancements yielding improved clinical outcomes.[80] Using the 2017 American College of Cardiology and American Heart Association's blood pressure (BP) guidelines, an estimated 103 million Americans have high BP.[1] These new BP guidelines have also redefined the clinical criterion for HTN to reflect a lower systolic threshold of 130/90 or higher compared to the previous systolic reading of 140/90.[80]

The percentage of adults diagnosed with HTN has increased from an estimated 32% to 46% since 2014.[80,81] African Americans (AAs), a group already disproportionately affected by HTN, remains adversely affected by these changes. Using the new parameters, it is projected that more than half of AA men (59%) and women (56%) will be reclassified as hypertensive.[81] In 2016, under the previous HTN guidelines, 42% of AA men and 46% of AA women were classified as hypertensive.[3] Furthermore, AAs 18-49 years are twice as likely to die from heart disease as whites, and AAs 35-64 years are 50% more likely to have HTN than whites.[7] As the diagnosis of HTN escalates,

more people will require pharmacotherapy together with recommended dietary and physical activity lifestyle mandates.

Blood Pressure Medication Adherence Statistics

To achieve optimal BP control, adherence to lifestyle regimens and BP medications must be a priority. Medication nonadherence is considered to be a modifiable contributor of the cardiovascular disparities between AAs and whites.[8] Poor BP medication adherence has been indicated as a significant risk factor of inadequate BP control in AAs.[68] Currently, there is no gold standard to adequately capture and measure the prevalence of medication adherence; thus the true rate is unknown.[69] Despite this imperfection, the odds of nonadherence to BP medications in AAs have been reported to range from 80% to 330%.[26] Adherence across hypertensive drug classes is also widely variable, with beta blockers ranging from a low of 28% to 65% among angiotensin receptor blockers.[82] A secondary analysis using the CDC's Behavioral Risk Factor Surveillance System data from 2011-2015 found a slight decrease in the overall prevalence of self-reported BP medication use.[70] The prevalence of antihypertensive use was highest among women (66.8%), Blacks or AAs (60.7%) and those in Southern states when compared to Western states.[70,83]. Additionally, Blacks were most likely to receive combination therapy and have the highest average number of prescribed BP medications. The rates of HTN control based on JNC-7 recommendations were also the lowest in Blacks (36.9%) and Hispanics (31.2%) compared to Whites (42.9%).[70]

Purpose

Barriers to achieving optimal BP control among AAs have been studied extensively.[5,11,27,28,60] Research regarding the factors that enhance optimal BP

medication adherence, specifically in young (<50 years old) adult AA women remains limited. AAs are diagnosed with HTN at earlier ages and incur cumulatively faster progression of organ involvement compared to other racial groups due to poorly controlled HTN.[10] Identifying factors influencing BP medication adherence in younger AA women is imperative to decrease the progression of poor outcomes associated with lifelong uncontrolled HTN.

Medication adherence is a complex phenomenon influenced by various dynamics including: *Social/Economic*, *Provider-Patient/Health care system*, *Condition-related*, *Therapy-related*, and *Patient-related*.[84] (See table. 1) These factors contribute to medication-taking nonadherence, including intentional (choosing not to take medications) or unintentional (intending to take medication in the right way but not doing so for various reasons).[31,84,85] The purpose of this review is to examine the known and unknown contributors of BP medication adherence using the aforementioned dynamics in young adult AA women. This review will also propose a conceptual framework [23,25,72] to answer potential research questions to understand the complex interrelationships of cognitive, psychosocial, and behavioral factors that influence BP medication adherence. This model may also serve as a framework, once validated, to guide targeted interventions directly impacting adherence, thus decreasing the HTN disparities gap.

Review of the Literature Antihypertensive Medication Adherence

Medication adherence – the following of a prescribed treatment regimen,[54,86] – has not been adequately achieved in AAs. Unfortunately, AAs sustain some of the worst cardiovascular outcomes associated with uncontrolled BP, including stroke, end stage renal disease, and early morbidity and mortality.[87] Many factors play a role in BP

medication adherence among AA women; many have been observed among older (>50) AA women. These include: age >50, knowledge, beliefs, and awareness surrounding HTN,[5] discovery of life's purpose and spirituality,[5,85] social support,[5,26,62,88] and collaborative patient-provider communication.[89,90] Regardless of age, these influences on BP medication adherence could also impact young adult AA women, given the similar cultural context.

Social/Economic Factors.

Demographic covariates including age, gender, race, and socioeconomic status (SES) are associated with optimal **and** poor medication adherence. However, demographic variables have been found to have inconsistent findings or no effect on medication adherence.[17] In a cross-sectional study examining medication routines among a hypertensive AA sample, younger participants demonstrated variable or inconsistent medication-taking routines compared to older participants, but this finding was not significant.[8] Similar to age, SES is another covariate considered a determinant of medication adherence. Blacks or AAs of a lower SES (low income, low education level, lack of insurance) have a greater propensity to demonstrate poor BP adherence routines.[91] Pre-existing stress, coupled with financial barriers, is also suggested as a barrier to BP control. Specifically, being of lower SES adds a layer of strain that makes it challenging to be adherent when faced with competing priorities.[5] These reported barriers validate previous studies among younger AA participants for poor adherence to BP medications, including themes of family care-giving, subordination of healthcare needs, and work obligations.[15,92] However, Kountz and Kofman[15] suggested not all low SES minority patients are likely to be poorly adherent with their BP regimen. Another study examining predictors of adherence among AA patients revealed a significant

gender split. Low SES male and higher SES female participants demonstrated better BP medication adherence.[61] One reason that could explain this relationship in women may be that higher SES women have the financial means to take on expenses with less difficulty than lower SES women. The association among low SES men could be attributed to message framing, receptiveness of information received, and provider relationship; however the study did not address these factors and this is speculative.

Provider-Patient & Therapy Related

Provider, patient, and therapy related factors are interrelated dynamics, which have a major impact on BP medication adherence in AAs.[92] Trust in the medical provider is cited as a major determinant of adherence to medical-directed regimens and the health outcomes achieved in AAs. [37] Historical events of medical maltreatment and research neglect are credited for the present culture of distrust among AAs.[92,93] However, trust is an essential bi-directional feature in the provider-patient relationship to foster collaboration, communication, and concordance between parties. Trust can be fostered among AAs who have insurance and see a consistent provider in an office setting versus places like an emergency room, urgent care, or community health center.[94] This outcome can likely be attributed to the continuity and consistency in care fostering an environment of trust, allowing the provider and the patient to establish a rapport and relationship. Time constraints that limit proper engagement and education have been reported as a system imposed-barrier by providers.[95] Clinician-based interventions attempting to focus on motivation and education to improve adherence have not garnered the success intended.[27] Unfortunately, this creates an additional layer of complexity making it difficult to promote needed trust and communication.

BP medication side effects pose as another barrier inhibiting BP control. Among some hypertensive AA women, reported side effects from BP medications were described as debilitating and disruptive, forcing them to make dosage changes or terminate the medication without notifying their provider.[5,26] Some reported side effects included lethargy, swelling, increased urination, and an overall feeling of sickness.[5,26] In a sample of hypertensive AAs, an inverse association was found between low adherence scores and high scores surrounding beliefs about BP,[96] indicating there is great concern surrounding the side effects of BP medications. Like trust, the ability to effectively communicate and report BP medication concerns to resolve issues is imperative in order to dismantle the barriers of poor medication adherence.[92]

Condition-Related

HTN has been commonly associated as a stress-related etiological illness.[27,29,97] The etiology of stress-derived HTN among AAs has been attributed to stressors evolving from racial and social inequity.[27] The asymptomatic nature surrounding HTN has been considered a barrier to treatment initiation and maintenance.[23,27] AAs have frequently associated elevated BP with somatic symptoms of headaches and dizziness.[5,27] Denial of a HTN diagnosis due to absence of symptoms has been reported among AA women.[5] HTN has also been reported as a transient illness that is inactive in the absence of symptoms, limiting the length of time required to maintain treatment for BP control.[27] In the absence of symptoms, conceptualization and operationalizing of a predominantly silent illness becomes difficult to ascertain to promote cardiovascular health.[23] The asymptomatic nature and discordant beliefs associated with HTN creates conflict between the patient and provider relationship. Greater awareness of the existence of

these perceptions and strategies to educate and minimize adverse cardiovascular outcomes are warranted among this vulnerable population.

Patient-Related Factors

HTN Illness Beliefs/Perceptions

Health beliefs are suggested to be a stronger predictor of medication adherence than demographic variables.[96] Beliefs surrounding the development of HTN may play an integral role in the increasing prevalence of HTN in AAs.[26,27,98] Illness beliefs or perceptions together with coping behaviors such as resilience, have also been suggested as shaping how individuals self-manage chronic conditions.[99] Adherence to BP medications has been associated with HTN beliefs recognizing the positive outcomes of the treatment, including BP control, heart attack prevention, and having a realistic view distinguishing the condition as a chronic long-term disease rather a short-term, stress-related illness.[26,28,98]

AAs tend to possess unique beliefs regarding the etiological dimensions of HTN, referred to as lay beliefs/perceptions (self-defined model or understanding of an illness) that oftentimes go against biomedical (providers') beliefs and have been considered key in medication adherence.[28,98] While discordant health beliefs may exist across ethnicities, studies have found that AAs were more likely to attribute HTN as a stress-driven disease and are less likely to associate HTN with age or heredity compared to whites.[5,29,98] In the absence of symptoms, operationalizing an asymptomatic condition presents a challenge for patients by hindering the adoption of a treatment plan deemed to improve overall cardiovascular health.[37] HTN beliefs can be recognized as a key

determinant facilitating or prohibiting BP medication adherence among a vulnerable group at-risk for poor cardiovascular morbidity and mortality.

Social Support

The relationship of social support and medication adherence has been well documented across various chronic illnesses. Social support consists of two domains: functional and structural. Functional support is the aid and encouragement provided to the individual by his/her social network, which is further operationalized as emotional, instrumental, and informative.[100] Structural support is the structure of an individual's network, primarily operationalized as being married or living with someone.[100] Contingent upon the individual's social support, its effectiveness can have a negative or positive impact on how a person self-manages and adheres to recommended health behavior and lifestyle changes.

Social Support is a key protective factor in reducing vulnerability to the adverse effects of stress on health.[101] The benefits of social support networks have been examined across various chronic diseases and include an increase in self-rated health, decreased psychological issues, and a decrease in recovery time from serious injury or illness;[59] however, social support as a predictor of medication adherence in AAs has been an inconsistent and weak correlate.[60,100] In a qualitative study involving a sample of hypertensive AAs, some of the participants did not find their social network to be helpful in managing their HTN.[62] Citing privacy issues, some participants stated displeasure with their support system being involved in their medical care.[62] A study examining the social support system of rural AA women 20-80 years of age with HTN

found their network less supportive when attempting to make necessary lifestyle modifications to manage HTN, including diet and physical activity levels.[63] Understanding the type of social support system in place among women demonstrating optimal medication adherence may help better inform interventions involving not only the patient but their support system.

Depressive Symptoms

AA women are plagued by unique behavioral and psychosocial factors that further heighten the risk for poor cardiovascular outcomes.[102] Depression is regarded as an unrecognized cardiovascular risk factor among AA women diagnosed with HTN.[64] The belief that strength must be demonstrated in the presence of challenges are suggested to have an adverse effect on both mental and physical health.[44] Cultural coping in AA women has been suggested as an antecedent for the development of chronic illness eventually contributing to early death for AAs.[44] Depression, regarded as a complex state of insight and crisis, cognitive awareness and compromised physiological functioning, often remains unrecognized by AA women and undiagnosed by health care providers.[64] This further adds to the burden of ineffective self-management strategies of BP medication adherence and coping with chronic HTN.[51] The presence of depressive symptoms compounds the risk for stroke in AA women.[103] Additionally, depressive symptoms may further heighten an individual's negative view of themselves and their current and future situations, thereby affecting cognitive attributes like motivation and limiting positive health behavior.[104]

Environment: Adverse Stress Exposure

Stressors are defined as the problems, hardships, or threats that challenge the

adaptive capacities of an individual.[42] Due to the current and historical inequities stemming from systemic and structural racism including housing, lower SES, and oppression, AAs are subjugated and predisposed to both acute and chronic stressors.[43,44] Young and old AA adult women share a commonality in the stressors experienced; however, younger adult AA women confront more stressors associated with balancing work and family,[42,44] adding another layer to their vulnerability. These stressors are suggested to be different than those experienced by men and have an adverse impact among AA women.[50-52] Repeated subjection to these stressors have predisposed AA women to poor health and even greater self-ratings of poorer health.[44] In both middle and low SES groups, AAs were found to experience a higher rate of exposure to stressors compared to whites[53,54] and were 2.26 times more likely to be exposed to traumatic life events after controlling for variables like education, gender, early misconduct, and history of psychiatric disorder.[55] AAs, specifically of a lower SES, are likely to engage in adverse health-related behaviors (overeating, drinking, smoking, drug abuse, physical inactivity) to ameliorate the effects of adverse stressors, further posing a threat in appropriately managing HTN or any illness.[105]

Coping

Psychosocial factors influence medication adherence, including coping behaviors. Coping strategies in AAs are suggested to be a byproduct of the inherent racial inequities encountered, including but not limited to: racial and gender discrimination, deprived neighborhoods, wage inequity, lower social status, and structural disadvantage.[36,43] Despite early life stressors and persistent adverse exposures, many AAs avoid ill health, negative well-being, and maladaptive coping behaviors to achieve a positive sense of

well-being and health.[38,39] Resilient coping, derived from psychological resilience, is considered to be an important protective behavioral factor in sustaining health and promotion of self-management behavior.[106]

Much of the resilience literature in AAs is centered on youth and behavioral development and functioning in the face of adversity, trauma, and adverse social conditions.[34,37,41] Resilience, which emanates from early locus of control studies, is a dynamic developmental process encompassing the ability to bounce back, overcome, and achieve a positive sense of well-being despite exposure to adverse circumstances and situations.[30,31] Resilience is suggested to be a changing feature with the tendency to alter according to life's circumstances.[35] The presence of depressive symptoms can negatively affect coping strategies by perpetuating poor medication adherence and ultimately, uncontrolled BP. Denial, avoidance, and problem-focused coping strategies have been examined for their impact on health outcomes;[22,23] however, resilient coping has not been examined as a strategy among hypertensive AA women.

Conceptual Model & Framework

Many health behavior models have come under scrutiny for their incomplete inclusion of important aspects influencing health behavior.[107] These contextual traits include but are not limited to the environment, sociodemographics, and past illness experience. Nonetheless, some models do a better job of capturing various attributes fostering and shaping health behavior. The Common Sense Model of Illness Representation (CSM) and the Transactional Model of Stress and Coping (TMSC) are two complementary health behavior change models, which examines how external and internal stimuli inform illness representations guiding coping behaviors and

outcomes.[22,72,107] Collectively examining illness perceptions and how they inform coping to influence medication adherence in young adult AA women may help explain the growing HTN disparities in AA women. See table. 2 of potential research questions that can be used to examine factors associated with adherence in chronic disease populations.

The premise of the CSM suggests that individuals create mental representations of their illness based on concrete and abstract sources of information available to make sense of and manage their illness.[22] The CSM is premised on 5 dimensions: (1) Identify, (2) Cause, (3) Consequences, (4) Timeline, and (5) Controllability/Cure.[25] Interpretation of the stressor/illness is determined to be mediated by the person's appraisal of the illness, in addition to the psychological, social, and cultural resources at their disposal.[25,72] Derived meaning from the information informs coping efforts geared toward problem management and emotional regulation. The CSM and TMSC offer key concepts that can assist in understanding how illness representations and coping inform health outcomes.

The concepts and models will be used to frame a study to examine relationships among psychosocial factors (depressive symptoms, racial and gendered stressors, social support), HTN illness perceptions, resilient coping, and BP medication adherence (See figure 1.1). Several studies have examined BP medication adherence in both AA men and women. However, this study is unique because few others have solely examined facilitators of BP medication adherence in young adult AA women utilizing the CSM and TMSC as guiding theoretical models. The knowledge to be gleaned from examining a population not well reflected in clinical research utilizing multidimensional models and

frameworks exploring HTN beliefs/perceptions in young adult AA women will be beneficial and add substantially to the current science.

Discussion/Conclusions

Concentrating on the social, psychosocial, and cognitive effects and their influence on HTN illness perceptions, resilient coping, and BP medication adherence is necessary for understanding HTN disparities. Poor cardiovascular outcomes and early mortality are direct clinical implications of inconsistent practices of BP medication adherence among young AA women, escalating the vulnerability of this group. The combination of the lived environment, psychosocial factors, and pre-existing experience with illness must be appreciated to understand the various factors impacting medication adherence. The susceptibility to competing demands and stressors that can distract young AA women from adherence to BP medications makes this group especially vulnerable for poor cardiovascular outcomes. Further research into the beliefs and coping behavior of young AA women will suggest where additional interventions should be directed to improve BP medication adherence.

Table 2.1 Barriers to Adherence

Social/Economic	Provider-Patient Related	Condition Related	Therapy Related	Patient-Related
Low education	Mistrust	Lack of knowledge regarding HTN	Medication side effects	HTN beliefs
Low income	Ineffective communication	Primarily an asymptomatic condition	Polypharmacy	Depressive symptoms & Ineffective coping response
Lack of health insurance	Provider non-adherence to treatment guidelines.	Length of illness-Acute vs. Chronic	Ineffective prescribed regimen	Demographics (age, gender, race)
Transportation and healthcare system access	Discordance between the provider and patient	Etiology of HTN viewed as a stress-related illness	Medication cost	Ineffective social support system
				Lack of a system to remember to take medications and get refills.

Table 2.2 Potential Research Questions Derived from Review.

Social/Demographic	Cognitive & Psychosocial	Cognitive & Behavioral
Do social factors (environment, social network system, interaction with people) positively or negatively influence medication adherence?	Is resilient coping a mediator of depressive symptoms and BP medication adherence?	Does exposure to contextualized racial and gendered stressors, social support, and depressive symptoms affect HTN illness perceptions, resilient coping, and BP medication adherence?
Is there a gender effect interaction between illness beliefs and BP medication adherence?	Does resilient coping have a direct effect on BP adherence?	Does length of HTN diagnosis have an effect on HTN illness perceptions and BP medication adherence?
Is resilient coping a predictor of BP medication adherence among low SES hypertensive women?	Does the presence of depressive symptoms adversely influence illness perceptions?	Does resilient coping moderate the relationship between high/low exposure to stressors and BP medication adherence?
Does the existence of functional social support impact BP medication adherence in AAs?		

Chapter 3

The Effect of Contextualized Racial and Gendered Stressors, Depression, and Social Support on HTN Illness Perceptions, Resilient Coping, and Hypertension Medication Adherence in Young Hypertensive African American Women

1. Introduction

Hypertension (HTN) is a modifiable, yet important predisposing risk factor for the development of cardiovascular disease (CVD) and other comorbid conditions.[1] Prevalence reports of HTN issues prior to the 2017 JNC blood pressure (BP) guideline changes identified Black or African American (AA) women as having a higher prevalence of HTN when compared to Black men (46% vs. 42%).[3] The new American College of Cardiology and American Heart Association (ACC/AHA) BP guidelines projects that more than half of both African American men and women will be categorized as hypertensive.[81] Among Black or AA women 20-44 years of age, the prevalence of HTN was more than double compared to White women of the same age group (16.6% vs. 6.6%).[108] Additionally, Blacks aged 18-49 years are twice as likely to die from heart disease as Whites.[7] Mounting evidence indicates that AA develop HTN at earlier ages, are less adherent, and more resistant to treatment.[5] Consequently, AA women are at a greater risk for developing comorbid conditions including, heart failure, stroke, kidney disease, and early mortality,[68,109,110] largely due to poorly controlled HTN (>130/90).

Poor adherence to prescribed BP lowering medications has been indicated as a major contributor to uncontrolled HTN among AAs, crossing both gender and

socioeconomic bounds.[68,91] The true prevalence of nonadherence to BP-lowering medication is considered imprecise due to the lack of a gold standard that properly identifies and measures medication nonadherence.[69] Regardless of this imprecision, researchers have found that Black-White differences in BP medication adherence exist.[8,91,111,112] Many of the patient-level factors associated with BP medication nonadherence in AAs, including HTN beliefs, adverse social stressors, coping, and mental well-being, are suggested to have their etiology in social determinants of health.[68,91,113] The interaction of race, gender, and socioeconomic status (SES) has been implicated in playing a significant role in both the psychological well-being and health behaviors of AA women.[42] Recognizing the impact and key role that social determinants have on the complex and interacting dynamics of various patient-level factors, including HTN beliefs, mental well-being, social support, and coping responses may provide the framework to develop tailored and culturally-targeted interventions to improve adherence among this at-risk group.

The purpose of this study is to examine the effect that exposures to contextualized racial and gendered stressors, social support, and depressive symptoms have on HTN illness perceptions, resilient coping, and BP medication adherence. The hypothesis of this study is that decreased exposure to adverse stressors, increased social support, and fewer depressive symptoms are associated with greater HTN illness perceptions, greater resilient coping, and greater BP medication adherence.

The conceptual model (figure. 1) used for hypothesis testing is adapted from Leventhal and colleagues'[23,24] 'Common Sense Model of Illness Perceptions' (CSM) and the Transactional Model of Stress and Coping (TMSC).[72] The CSM proposes that individuals create mental representations of their illness based on concrete and abstract

sources of information (ex. family, friends, social environment, medical providers) in order to make sense of and manage their diagnosis.[23] These internal and external stimuli combine to formulate the type of coping response that will be engaged to manage the stressor.[72] This bidirectional relationship is constantly being appraised based upon the outcome obtained.[23,25] Illness representations are comprised of the following five dimensions: *identity* (label or name associated and perceptions of associated symptoms/conditions), *cause* (beliefs of what caused the illness), *timeline* (beliefs associated with disease/illness onset, duration, and decline), *consequences* (anticipated effects the illness will have on one's life – physical, cognitive, social disruption), and *cure/controllability* (cure vs. control; self vs. medical provider).[25] Further, these mental illness representations influence how individuals will cope with the health threat that will further influence the health behavior. If HTN is perceived as a long-term condition with serious consequences if not properly managed, there is a greater likelihood the benefit of taking prescribed medications will outweigh the perceived risks, thus limiting concerns of potential medication side effects.

1.1 Racial and Gendered Stressors in Black Women

Stressors are defined as the problems, hardships, or threats that challenge the adaptive capacities of people.[42] Unfortunately, AAs are at greater risk for experiencing life stress, adversity, and their associated adverse health consequences compared to other racial/ethnic groups.[19,50,113] Stressors unique to AAs have been commonly associated with adverse circumstances such as racial and gender discrimination,[50,63] residence in disadvantaged neighborhoods,[114] wage inequity,[102,115] and lower social status/structural disadvantage.[43,50,102] The stressors juxtaposed with the unique stressors for Black women, including gender and role expectations in their families,

neighborhoods, and the workplace, have been indicated as a major cause of racial health disparities.[116] Cultural values, behaviors, and attributes of less powerful groups are frequently undervalued and considered to go against the norms of the more dominant culture, thereby leading to the persistent threats and identity of women, minorities, and those from low socioeconomic groups.[50]

African American adult women, both young and old, share a commonality in the stressors experienced. However, younger adult AA women confront more stressors associated with balancing work and family, adding another layer of complexity to their vulnerability.[42,44] These stressors are slightly different than those experienced by men and may have an adverse impact on AA women.[50,51] Repeated subjection to these stressors predisposes Black women to poor health and even greater self-ratings of poorer health.[44,117] In both middle and low socioeconomic status (SES) groups, AAs have been found to experience a higher rate of exposure to stressors compared to Whites,[53,118] and were 2.26 times more likely to be exposed to traumatic life events after controlling for important variables such as education, gender, early misconduct, and history of psychiatric disorder.[55] Weathering, a term developed by Geroniums, proposes that due to the cumulative stressors and repeated exposures to social and economic adversity experienced by Blacks or AAs, these stressors will eventually have a deleterious effect on overall health, thereby increasing vulnerability to illness and disease.[56] As a result of the subjugation to these stressors, AAs, specifically of a lower SES, are likely to engage in adverse health-related behaviors (drinking, smoking, drug abuse, physical inactivity) to ameliorate the effects of adverse stressors, further posing a health threat to appropriately managing HTN or other illness.[57]

1.2 Social Support

Social support serves as a key protective factor in reducing an individual's vulnerability to the adverse effects of stress on health.[119] The positive benefits of social support networks have been widely examined across various chronic diseases and include an increase in self-rated health, decreased psychological issues, and a decrease in recovery time from serious injury or illness;[59,100,120] however, social support as a predictor of medication adherence in AAs has been considered an inconsistent and weak predictor.[62,121] In a qualitative study involving hypertensive AA participants, some of the study participants did not find their social network to be helpful in managing their HTN.[62] Some participants did not like the idea of their support system being involved in their medical care, citing privacy issues.[62] A study examining HTN in middle-aged AA women residing in a rural southern state found the social support system to be less supportive when attempting to make warranted lifestyle modifications.[121] Some of the reported issues encountered included incongruence with their spouse and children in establishing and maintaining dietary changes and increasing physical activity levels, which made lifestyle changes difficult to maintain.[121]

1.3 Depressive Symptoms

Depression, regarded as a complex state of insight and crisis, cognitive awareness, and compromised physiological functioning, is regarded as an unrecognized cardiovascular risk factor among hypertensive Black women.[65] The triangulation of race, sex, and SES has been implicated in adversely affecting the psychological well-being of Black women.[42,50] The interaction of the lived environment, illness beliefs, and coping response mechanisms are believed to play an important role in the health outcomes of AA women.[44] The life experiences of AA women, in contrast to White women, tend to reflect the following: single head of households, residence in poorer, segregated, and

high crime neighborhoods, familial caregiving burden, and managing the ills of racism and sexism.[64,122] Unfortunately, the stressors faced by AA women are not isolated, but tend to coexist, further potentiating the risk of developing depressive symptoms and CVD, [122] and further adding to the burden of ineffective self-management strategies, including BP medication adherence.[117]

African American women are believed to be unaware of the presence of depressive symptoms.[123] This is due to the personification and stigma surrounding depression as a sign of weakness, and, as a result, remains undiagnosed by health care providers.[64,65] The lack of recognition of depressive symptoms or depression among AA women has been attributed to cultural coping and the perceptions held from older generations.[44] Cultural coping in AA women has been suggested as an antecedent for the development of chronic illness that may eventually contribute to an early mortality.[66] Multiple studies, including those with African American samples, have reported findings demonstrating the presence of depressive symptoms being associated with poorer medication adherence, compared to those who were not depressed.[43,64,104] Additionally, stroke risk is further heightened among AA women with untreated depressive symptoms and poorly controlled BP.[67]

1.4 Resilient Coping

Resilient coping, derived from psychological resilience, is considered to be an important protective behavioral factor in sustaining health and promotion of self-management behavior, however the relationship between resilient coping and health is not clearly understood.[30,31] Resilience, which emanates from early locus of control studies, is conceptualized as a dynamic developmental process encompassing the ability to bounce back, overcome, and achieve a positive sense of well-being, despite exposure

to adverse circumstances and situations.[32,124] Resilience is suggested to be a fluid attribute that has the tendency to change according to an individual's life circumstances.[35,125] AAs are at an increased risk for experiencing early life stressors and adverse situations.[36,37] Despite subjection to early life stressors and persistent adverse exposures, many African Americans actually avoid ill health, negative well-being, and maladaptive coping behaviors to achieve positive health.[38,39]

Much of the resilience literature in AAs has focused on AA youth relative to behavioral development and functioning in the face of adversity, trauma, and adverse social conditions.[34] The relationship of resilient coping as a protective behavioral factor in attaining positive health behaviors in the presence of various stress exposures has not been well represented in the resilience literature, however.[30] The development of symptomatology across various chronic illnesses are believed to be influenced by the activation of the biological, neuroendocrine, and immunological systems, thus influencing psychosocial factors, including coping behaviors.[30] How an individual copes in managing an illness will play a significant role in the efficacy of managing the illness.

1.5 HTN Illness Perceptions

HTN illness perceptions, also referred as beliefs, have been closely attributed to HTN disparities, especially among AAs.[25,97,98] Among AAs and minorities, HTN illness perceptions are suggested to be driven significantly by both cultural and social factors that are thought to also hinder engagement in treatment.[27,98] Evidence suggests AAs perceive HTN to be a common and unavoidable stress-related illness, subject to occur at some point during their lifetime.[27] Among AA women, HTN is believed to be a symptomatic condition, which is the byproduct of emotional stress.[5,29] The idea of

having a HTN diagnosis in the absence of symptoms poses a barrier by inhibiting the adoption of a treatment plan that is deemed to improve overall cardiovascular health.[23]

Illness representations consist of cognitive and emotional representations, lay information, external sources, and existing or previous experience with a condition or illness.[25] They are created and initiated by somatic sensations and deviations from normal function (ex. chest pain, headache), observation and discussion of illness in others (ex. medical diagnosis), mass media, and other environmental stimuli.[25] Collectively, these stimuli activate prototypes or memory structures of the individual's normal functional self, past experience with illness, treatments, and lifestyle activities, generating mental representations of illness threats (beliefs surrounding illness, identity, cause, control, consequences, and duration/timeline beliefs), potential treatments, and the formation of action plans.[25] Based upon an individual's illness perception, engagement in treatment and self-management behavior, such as medication and lifestyle adherence, can be negatively or positively influenced.

1.6 BP Medication Adherence

Hypertension medication adherence (the extent to which patients take their medications as prescribed by their medical providers)[82,126] and BP control have not been adequately achieved in AAs.[91] Poor BP medication adherence has been indicated as a significant factor responsible for inadequate BP in AAs.[68] Among adults 20 years of age and older without kidney disease, optimal BP control is defined as a BP less than 120/80 or less than 130/80 in the presence of either kidney disease or diabetes.[127]

Prescribed use of BP medications increased among young adults from 2001-2002 (35.7%) to 2009-2010 (43.5%) and in women (68.6% vs. 82.5%), reflecting the increased incidence of HTN. The estimated rate of nonadherence to BP medications

among AAs ranges from as high as 80% to an astounding 330%; however, specific rates of nonadherence are considered imprecise, due to the lack of a gold standard that properly identifies and measures nonadherence rates to medications.[69] As hypertensive studies continue to identify young AA women as less adherent, specific rates of nonadherence remain unclear, further necessitating the urgency to understand how this vulnerable group self-manages HTN.

2. Methods

The present study, embedded in a larger observational cross-sectional study, examines BP medication adherence among a sample of hypertensive AA women 18-45 years of age. Women were eligible to participate if they: were at least 18 years of age, were born in the United States, identify as Black or AA by race, received a medical diagnosis of HTN from a clinician, were prescribed at least one BP-lowering medication, and comprehend written and spoken English. Exclusion criteria included: non-Black or African American race, younger than 18 years or older than 45 years, non-English speaking, severe learning or cognitive disabilities, and pregnant women. Participants were recruited from community health screenings and cardiology and internal medicine ambulatory clinics. Institutional review board (IRB) approval for this study was received from Emory University and Grady Health IRB. Participants completed and signed informed consent.

2.1 Measures

The following variables measured for this study include: socio-demographic (age, education, income, health insurance), clinical (blood pressure, BMI, weight, comorbidities), cultural context (stress exposure), psychosocial (social support, depressive symptoms), and cognitive and behavioral (HTN illness perceptions and

resilient coping) factors. Demographic and study questionnaires were completed via iPad with paper forms utilized as a backup in the event of no Internet access.

2.2 Blood Pressure, Lipids, Demographics

All participants rested in a seated position with both feet flat on the floor for at least five minutes prior to having their BP measured. BP measurements were obtained using the automated Omron 10 series machine. The average of three BPs was taken at least 30 seconds apart and recorded. Lipid testing was done using the Cardiochek PA analyzer. Demographic data, including height and weight, was obtained via self-report or review of medical records.

2.3 Medication Adherence

The *Adherence to Refills and Medication Scale* [ARMS-7] assesses medication-taking behavior and medication refills. The scale is an abbreviated version of the ARMS-12 and consists of two subscales and seven items used to measure adherence, which is the outcome variable of this study. The total scale score is obtained by taking the sum of all seven items. Scores can be interpreted as either continuous or dichotomized based on the instrument's cutpoint score of 'seven' indicating perfect adherence or higher suggestive to some degree of non-adherence.[77] The instrument was developed utilizing a hypertensive minority patient population in a large urban medical center and has been well-validated with a demonstrated Cronbach's alpha ranging from 0.81-0.82.[77] The Cronbach's alpha value for this study is 0.75. The score range for this instrument is 7-25.

2.3 Resilient Coping

The *Connor-Davidson Resilience Scale* (CD-RISC 10) was used to measure resilient coping. The CD-RISC 10 is a 10-item scale that measures resilience, a multidimensional characteristic that varies based on context, gender, age, cultural origin, and age.[73] The CD-RISC 10 is one of two brief versions of the resilience scale, and it is comprised of items from the original CD-RSIC 25 item scale.[73] Scoring of the scale is additive, and ranges from 0-40 with higher scores indicative of greater resilience. The CD-RISC has been well validated with a Cronbach's alpha value of 0.85.[33] The Cronbach's alpha value of the scale for this study is 0.89.

2.5 Lifetime Racial and Gender Discrimination Events

The *Lifetime Racial and Gender Discrimination Experiences* scale is comprised of questions from both the Schedule of Racist (SRE) and Sexist (SSE) Events, two instruments that were designed to measure social stressors of racial and gender discrimination respectively. The total scale consists of 22 items, 10-items from the SSE and 12-items from the SRE, which are measured on a 4-point Likert scale.[50] Sample questions from the SRE and SSE include, "How many times have you been treated unfairly by your employers, bosses, and supervisors because you are Black?" and "Have people made inappropriate or unwanted sexual advances at you?" The score from the SSE_SRE is a continuous measure and does not have a cutpoint score. Higher scores are indicative of greater adverse stress exposure. The total scale Cronbach's alpha value is 0.88, SRE is 0.90 and SSE is 0.84.[50] In this study, the total scale had a comparable Cronbach's alpha value of 0.88.

2.6 Hypertension Illness Perceptions

The *Brief Illness Perception Questionnaire* [BIPQ] is an eight-item Likert-type scale assessing the dimensions of HTN, including: consequences, timeline, personal

control, treatment control, identity, coherence, emotional representation, and illness concern.[74] Item nine of the BIPQ assesses the causal dimension of HTN where respondents can enter up to three causes of their HTN. Responses from this question were categorized by themes and analyzed. A total scale score was obtained by computing the mean across all items. In addition, each dimension was entered into the model to examine its association with medication adherence. A sample question from this scale reads, "How much does your high blood pressure affect your life?" The Cronbach's alpha value for this scale ranges between 0.87-0.90.[74] The Cronbach's alpha value of the composite score for this study is 0.68.

2.7 Social Support

The *Enhancing Recovery in Coronary Heart Disease Social Support Inventory* (ENRICHD) was used to measure social support. This seven-item self-report instrument has been used across a variety of chronic disease populations. The instrument consists of four domains of social support: emotional, instrumental, informational, and appraisal; scores higher than 18 are indicative of high social support.[120] The total instrument Cronbach's alpha value is 0.88.[75] The Cronbach's alpha value of the tool for this study is 0.85.

2.8 Depressive Symptoms

The *Patient Health Questionnaire* (PHQ-8) is a diagnostic and screening tool for depressive symptoms. The PHQ-8 was adapted from the PHQ-9 and omits one question on suicidal ideation. The score range for the PHQ-8 is 0-3, with a maximum score of 24.[128] As a screening tool, a score of 10-14 is considered to be indicative of moderate depressive symptoms.[128] This instrument has been validated and used across a variety of

illness populations.[129] The Cronbach's alpha value for the scale is 0.86.[128] The Cronbach's alpha value of the tool for this study is 0.89.

2.9 Data Analysis

Data analysis was performed using STATA version 15.1 for MAC (College Station, TX), with a significant alpha value set at $p < .05$. Study data were collected and managed using REDCap electronic data capture tools hosted at Emory University. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. Initial data analysis included descriptive statistics and examination of data to determine if assumptions for statistical test have been met.

Bivariate associations of covariates and independent variables of stress exposure, social support, and depressive symptoms were used to identify which variables were significantly associated with HTN medication adherence, HTN illness perceptions, and resilient coping. Stress exposure, social support, and depressive symptoms were entered into the model using multivariate logistic regression as a predictor of medication adherence. Using sequential regression blocks and stepwise variable selection methods within blocks, variables were entered into the model and optimally selected based on a probability value of less than 0.5. Interpretation of the data will hinge on the significance and the hypothesized direction of the relationships.

3. Results

3.1 Participant Characteristics

All women (N=85) participating in this study identified as AA, had self-reported a current diagnosis of HTN, and had been prescribed an BP medication. Demographic and physiological characteristics of the sample are presented in Tables. 3.1. The women were a mean of 39.2 ± 5.4 years of age with a mean BMI of 35.5 ±8.9. The majority of the women was insured (94%), single, had some college education, had relatively high social support and were non-adherent as determined by their ARMS-7 scores. Although mean PHQ-8 scores were low, 24% were considered to be in the range of moderate depressive symptoms. SSE_SRE scores were at the 50th percentile suggesting moderate exposure to lifetime racial and gender discrimination experiences.

3.2 Bivariate Analysis

Chi-square, t-test, and Pearson's correlational analysis were used to examine the association between socio-demographic covariates and predictor variables. Systolic BP was the only statistically significant covariate (r=-0.24, p=0.02) associated with adherence status. There was a significant difference in the mean systolic BP between adherent (M=129.4, SD=13) and non-adherent status (M=139.1, SD=15.8) (t=2.3(83), p=0.03) (See table 3.2). The composite score for HTN illness perception did not correlate with adherence; however, each dimension was entered separately to test for differences between the 'adherent' and 'non-adherent' group. There was a significant difference between adherent, (M=4.3, SD=3) and non-adherent (M=6.3, SD=2.8) status on the 'consequence' (How much does your blood pressure affect your life?) dimension of HTN (t= 2.51(83), p=0.01) and the 'identity' (How much do you experience symptoms from your high blood pressure?) dimension between adherent (M=3.8, SD=2.7) and non-adherent (M=5.6, SD=2.7) groups, (t=2.5(83), p=0.02).

Pearson's correlation (table 3.3) were used to examine the associations among covariate and independent variables with HTN illness perceptions and resilient coping. Systolic BP (r=0.26, p=0.02), socioeconomic variables of income (r=-0.24, p=0.03), insured status (r=-0.32, p=<.01), and education (r=-0.36, p=<.001) correlated with HTN illness perception score. Depressive symptoms was the only predictor variable associated with HTN illness perception (r=0.49, p=<.001). Resilient coping was significantly associated with income (r=0.36, p=<.001) and education (r=0.44, p=<.001). Social support (r=0.26, p=0.02) and depressive symptoms (r=-0.52, p=<.001) were the only predictor variables that were associated with resilient coping.

3.4 Regression Analysis

Covariates and clinical variables of age, income, comorbid status, weight, systolic, and diastolic BP were tested for their relationship with medication adherence (See table 3.4). Among the demographic covariates (Model 1, table 3.4), income was the only significant predictor of adherence, indicating after holding age constant, as income increased, the odds of adherence increased by 1.80, p=0.03. Among the clinical covariates, systolic BP was the only significant variable in the model (Table 3.4, model 2,). As systolic BP increased, the odds of adherence decreased by 0.95. Independent variables were tested for their relationship with adherence (Table 3.4, model 3,); however, none of the variables were associated with adherence. Criteria for stepwise backward selection estimation were set using a probability value of 0.05 and less than .10 for inclusion and variable removal from the model. Beginning with the full model, predictors and covariates were entered into the model to examine their association with adherence (Table 3.4, model 4). The 'consequence' dimension from the HTN illness perceptions scale was the only significant predictor remaining in the model that met

inclusion criteria, whereas the 'identity' dimension, social support, and income were not retained for the final model. Due to concerns of multicollinearity between SBP, the 'consequence', and 'identity' dimensions of the HTN illness perception scale, the model was tested without the HTN illness dimensions and further examined to assess for changes in predictors of medication adhernce. When age, income, systolic BP, and social support were entered into the model, systolic BP was the only significant predictor remaining in the final model that met inclusion criteria whereas the remaining variables were not retained for final entry (Table 3.4, model 5).

Multiple linear regression was performed to examine covariates as predictors of HTN illness beliefs (See table 3.5) and resilient coping (See Table 3.6). After controlling for socio-demographic variables of age, income, and education (Table 3.5, model 1), education ($F=2.52$, $p=0.01$) was the only significant covariate with HTN illness beliefs. None of the clinical predictor variables had a significant relationship with HTN beliefs (Table 3.5, model 2). Social support, depressive symptoms, and lifetime exposure to racial and gender discrimination were entered into the regression model. Increased depressive symptoms were the only predictor with a significant relationship with HTN illness beliefs (Table 3.5, model 3). Backward variable selection was used to test predictors of HTN illness beliefs (Table 3.5, model 4). Beginning with the full model, HTN illness perceptions, income, SBP, depressive symptoms, social support, and exposure to racial and gender discrimination were tested for entrance into the model. Higher depressive symptoms ($\beta=1.11$, $p=<.01$) and increased systolic BP ($\beta=.22$, $p=<.01$) were the remaining predictors in the final model (Table 3.5, model 4). The results of the regression indicated the two predictors explained 31% of the variance ($R^2=.31$, $F(2,82)=18.53$, $p=<.001$) for HTN illness perceptions.

None of the clinical covariates had a significant relationship with resilient coping. Sociodemographic variables were tested for their association with resilient coping. Higher income ($F=4.12$, $p=>.01$) had a statistically significant relationship with resilient coping (Table 3.6, model 1). Predictors of resilient coping using backward variable selection regression method indicated two variables: low depressive symptoms ($\beta=-0.57$, $p=<.01$) and higher education ($\beta=2.18$, $p=<.001$) resulted in better coping and explained 39% of the variance ($R^2=.39$, $F(2,79)=25.34$,$p=<.001$) for resilient coping (Table 3.6, model 4).

Discussion

This paper examined the relationships of racial and gendered stressors, social support, and depressive symptoms with BP medication adherence, HTN illness perceptions, and resilient coping among a young, hypertensive population of Black women. To the author's knowledge, there are no other studies that have examined these factors in this population and age group of women. The majority of the sample was categorized as non-adherent with their BP medications. The instrument's cutpoint score of seven identifies perfect adherence, eliminating the potential to deviate from behavioral practices associated with medication-taking. For instance, if a participant sometimes or occasionally failed to plan ahead in refilling their medications, this would increase the likelihood for non-adherence. Group differences were observed for systolic BP between the adherent and non-adherent group. Specifically, adherent participants SBP was ten-points lower than the non-adherent group. This is an important clinical observation that suggests when medications are taken as ordered, they are effective. Since this is a cross-sectional study, participants' baseline BP measurement was not

collected nor examined to compare pre and post treatment. Nonetheless, this is an important indicator of the relationship between medication adherence and SBP control.

The HTN illness perception composite score did not correlate with medication adherence; however, each dimension, with the exception of the causal dimension, was tested separately for its association with BP medication adherence. Both the 'consequence' and 'identity' dimension had a significant relationship with medication adherence when entered separately into the regression model but when tested together with the remaining predictors, the effect was attenuated and no longer significant. Greater perceptions of adverse consequences associated with HTN increased the odds of non-adherence. According to the presuppositions of the CSM, having a more negative view surrounding the 'consequences' of an illness should inform the coping process thus increasing the likelihood of the desired health response due to the perceived seriousness of the condition;[23] however, the opposite relationship was demonstrated in this study. Interestingly, AA women who had higher scores in the 'consequence' and 'identity' dimensions of the HTN illness perception scale, had a more threatening perception of HTN as an illness that was also associated with medication non-adherence. Hypertensive AA women that believed HTN severely affects their life in addition to experiencing more symptom burden as a result of HTN were non-adherent. This is an important clinical observation that warrants further attention since current studies suggest that women 55 years of age and younger are likely to fare worse after having a myocardial infarction, an important predisposing risk factor of HTN, when compared to men.[130] Prevention is essential in order to decrease the prevalence of racial and gendered HTN disparities.

Income was a significant covariate associated with medication adherence and HTN illness perceptions. Income and education are key social determinants that have been suggested to have a significant impact on the health outcomes achieved in populations.[131] Our study findings observed a positive relationship between increasing income levels and medication adherence. Previous studies examining medication adherence have yielded inconclusive findings with socio-demographic variables.[132] The majority of the women in this study were employed, educated, and had health insurance, which could have explained these relationships. Considering these associations, the majority of the women in this sample were also categorized as non-adherent despite having higher education and health insurance.

Resilient coping was neither associated with medication adherence or HTN beliefs; however, a significant relationship was found with income and education covariates. Higher education and greater income was associated with resilient coping suggesting that greater education may enable one to actively and effectively cope and problem solve the hardships of life. This is congruent with the proposed hypothesis by Chen and Miller which posits to 'Shift and persist', qualities that enable persons to respond to stressors thru the use of emotional regulation coping strategies, especially among those subjected to life adversity, may play an important role in the development of resilience.[133] The ability to shift or adapt during times of adversity is believed to help find meaning, while maintaining a sense of hope or optimism when facing adverse situations.[133] As a result of the two behavioral processes, adverse physiological responses created by stressful situations, is suggested to decrease the pathogenic precursors for disease or chronic illness development.[133] Likewise, greater income, specifically $48,000-$96,000 annually, was associated with higher resilient coping

scores, indicating greater financial security. The linkage between SES and health has been extensively studied.[134-136] Among minority populations specifically, cultural values that promote increased growth including educational attainment, has been postulated to promote resilience.[133] Financial security provides a sense of protection that creates access to needs beneficial for health; the relationship of resilient coping could provide some relevant insight into the role of resilience as a coping mechanism that could potentially serve as a buffer from the adverse effects of stress exposure. More evidence is needed to better understand this relationship and its effect on health behaviors.

Neither adverse stress exposure nor social support was associated with HTN illness perceptions or resilient coping as hypothesized; however, depressive symptoms had a statistically significant relationship to both. A more threatening perception of HTN was associated with increased systolic BP and greater depressive symptoms. Since this study is cross-sectional, it is not possible to determine if the depressive symptoms appeared prior to the HTN diagnosis or vice versa. Nonetheless, the presence of depressive symptoms in conjunction with a threatening perception of HTN, could inform the clinical assessment as well as development and testing of future targeted interventions focused on HTN beliefs. Despite the lack of significance of adverse social stressors in the present study, stress has been indicated as a key factor for the development of HTN.[27,137] With respect to this association, as resilient coping increased, depressive symptoms decreased, which supports the study hypothesis.

The findings from this study should be interpreted with caution due to some limitations. First, this is a cross-sectional study, so temporality cannot be established. Second, the findings from this study may not be generalizable to a broader population because of the predominantly sample of African American or Black women. Although

this is a limitation, having a predominant heterogeneous sample of African American women contributes to an increased understanding of the multifactorial nature underlying BP medication adherence. In addition, these findings may not apply to the broader population of AA women since this sample were actively seeking healthcare for the management of their HTN. This demonstrates a level of involvement in their healthcare regardless of the high number of participants who were considered nonadherent to their medications. Third, this study used a subjective self-report for all concepts under study, including medication adherence, thus increasing the chance for over- or underreporting of responses. However, eliciting self-report of this behavior is widely used due to ease of administration and cost. In addition, the reliability of the HTN illness perception scale was less than comparable for this study sample. Previous studies that have utilized this instrument had less diverse samples, which is an important factor to consider in ethnic minority populations. Fourth, there were more non-adherent respondents compared to adherent, thus impacting the results obtained. Finally, the sample size for this study was small so replication of this study in a larger sample would be ideal to determine if these relationships would differ.

Overall, this study provided some relevant insights into the relationships of important predictors of BP medication adherence among a sample of young adult hypertensive AA women. AA women are faced with stressors that differ compared to White women and gaining a better understanding of key factors that impact the ability to effectively self-manage HTN is necessary to better manage HTN. It is imperative for clinicians and public health professionals to examine the various factors ranging from sociocultural, social context, and illness beliefs that can significantly impact HTN

outcomes among this vulnerable group. The ability to do so could potentially improve adherence thus decreasing the progression of CVD.

Table 3.1 Demographic and Physiological Characteristics of Participants (N=85)

Characteristics	N(%) or mean (± SD)	Range
Demographics		
Age	39±5.4	24-45
Income		
Less than $12,000/year	15 (18.3)	
$12,000-$24,000/year	7 (8.5)	
$24,000-$48,000/year	30 (36.6)	
$48,000-$96,000/year	18 (22)	
$>$96,000/year	12 (14.6)	
Health Insurance		
Yes	79 (94)	
No	5 (6)	
Education		
9th-12th grade	6 (7.1)	
HS graduate	12 (14.3)	
Some College	26 (31)	
College Graduate	28 (33.3)	
Post-Graduate	12 (14.3)	
Marital status		
Yes	33 (39)	
No	52 (61)	
Clinical		
Comorbidities	12(14%)	
Systolic BP mm Hg	137.2±15.7	106-168
Diastolic BP mm Hg	88.8±12.1	56-127
BMI	35±8.9	20.4-67.9
Weight (lbs)	213.5±55	122.4-411
Cholesterol (mg/dl)		
Total cholesterol	176.4±37.3	96-259

HDL	53±15.2	12-95
LDL	100±41	31-282
Measures		
Adherent		
Yes	16 (18.8)	
No	69 (81.2)	
Adherence (ARMS-7)	11.5±3.9	7-25
Illness Perception (BIPQ)	41±12.6	7-68
Resilient Coping (CDRISC-10)	29.1±7	12-40
Depressive Symptoms (PHQ-8)	6.4±5.6	0-24
Social Support (ESSI)	21.4±5.4	6-28
Lifetime Racial & Gender Discrimination Events (SSE_SRE)	42.1±12.3	22-72

Key: BMI-body mass index; BP-systolic blood pressure; ARMS-7-Adherence to refills and medications scale; BIPQ-Brief illness perception questionnaire; CDRISC-10-Connor-Davidson Resilience Instrument Scale; PHQ-8-Patient health questionnaire; ESSI-Enhancing Social Support Inventory; SSE_SRE-Lifetime racial and gender discrimination experiences.

Table 3.2 T-test for group differences between Adherent and Non-Adherent

	Adherent			**Non-Adherent**			**95% CI for mean difference**	t	df
	M	SD	N	M	SD	N			
SBP (mm Hg)	129.4	13	16	139.1	15.8	69	1.25, 18.14	2.28	83
DBP (mm Hg)	86.3	17.60	16	89.3	10.51	69	-3.66, 9.70	0.89	83
Adv Stress	38.4	11.38	16	42.9	12.5	69	-2.22, 11.32	1.22	83
Soc Supt	23.73	5.40	15	20.9	5.56	69	-5.89, 0.13	-1.90	82
Dep Sx's	4.81	4.21	16	6.75	5.82	69	-1.14, 5.01	1.25	83
Res Cope	31.3	7.48	16	28.6	6.88	69	-6.47, 1.25	-1.35	83
HTN Belief	36	11.43	16	42.1	12.7	69	-.77, 13.01	1.77	83
Cons.	4.31	3.00	16	6.30	2.82	69	.42, 3.57	2.52	83
Time	5.94	3.32	16	5.83	3.71	69	-2.12, 1.90	-0.11	83
Persn Ctrl.	4.19	2.88	16	4.20	2.70	69	-1.49, 1.52	0.02	83
Trtmt	1.93	1.44	16	2.94	2.20	69	-.15, 2.16	1.74	83
Ident.	3.75	2.65	16	5.59	2.68	69	.37, 3.32	2.49	83
Illn Conc.	8.69	3.05	16	8.51	2.27	69	-1.52, 1.16	-0.27	83

Coher	1.90	1.63	16	2.78	2.44	69	-.37, 2.18	1.42	83
Emot Rep	5.31	2.98	16	5.96	3.33	69	-1.16, 2.45	0.71	83

Key: SBP-systolic blood pressure; DBP-diastolic blood pressure; Adv Stress-Lifetime exposure to racial and gendered stressors score; Soc Supt-Social Support; Dep Sx-depressive symptoms; Res Cope-Resilient Coping; Illn Belief-HTN illness beliefs; Cons-'Consequence' dimension; Time-'Timeline' dimension; Persn Ctrl-'Personal Control' dimension; Trtmt-'Treatment' control dimension; Ident.-'Identity' dimension; Illn Conc.-'Illness Concern' dimension; Coher-'Coherence' dimension; Emot Rep-'Emotional Representation' dimension

Table 3.3 Correlation Matrix

Variables	1	2	3	4	5	6	7	8	9	10	11
1. Adh	-										
2. SBP	-0.24*	-									
3. Diastolic	-0.10	0.55***	-								
4. Income	-0.25*	-0.06	0.12	-							
5. Education	0.13	0.01	0.09	0.65***	-						
6. Insured	0.12	-0.31***	-0.16	0.33***	0.21	-					
7. Adverse stressors	-0.15	0.21	0.09	0.25*	0.23*	0.06	-				
8. Social support	0.21	-0.05	-0.04	0.08	0.03	0.03	-0.30**	-			
9. Illness beliefs	-0.19	0.26*	0.16	-0.24*	-0.36***	-0.32***	0.21	-0.15	-		

10. Resilient Coping	0.14	0.11	0.12	0.36***	0.44***	0.15	-0.05	0.26*	-0.28**	-	
11. Depression	-0.14	-0.02	-0.12	-0.18	-0.16	-0.20	0.22*	-0.30**	0.49***	-0.52***	-

KEY: Adh-Adherent category; SBP-systolic blood pressure; Insured-Health insurance; *denotes p-value significance at <0.05; **<.01; *<.001**

Table 3.4. Summary of Multivariate Logistic Regression Analyses for covariates and predictors of Adherence

Variables OR (SE)	Model 1 X^2=4.88	Model 2 X^2=6.79	Model 3 X^2=11.49	Model 4 X^2=4.70	Model 5 X^2=6.60
Age	0.98 (0.06)				
Income	1.80 (0.65)*				
Education	0.93 (0.33)				
BMI		0.95 (0.04)			
SBP		0.95 (0.02)*			0.95(0.02)
DBP		1.02 (0.03)			
Comorbidity		1.33 (1.31)			
HTN illness perceptions composite			1.02 (0.04)		
'Consequence dimension'			0.81 (0.11)	0.80(0.09)*	
'Identity dimension'			0.80 (0.13)		
Social support			1.10 (0.08)		
Depressive symptoms			1.03 (0.08)		
Racial and sexist stressors			0.98(0.03)		

Resilient coping			1.01 (0.06)		
Constant	**0.13 (0.44)**	**239.22 (737.10)**	**0.15 (0.42)**	**0.72 (0.43)**	**220.10 (633.13)**

***Denotes significance at <.05 level;**

Table 3.5. Multivariable Linear Regression Results for the HTN Illness Perceptions with final predictors

Variables β (se)	**Model 1 F=2.52 ($_{df}$81)**	**Model 2 F=2.78 ($_{df}$82)**	**Model 3 F=8.84 ($_{df}$83)**	**Model 4 F=18.53 ($_{df}$84)**
Age	0.19 (0.25)			
Income				
$12K-$24K	0.10 (5.77)			
$24K-$48K	-0.22 (4.31)			
$48K-$96K	-0.14 (5.38)			
>$96K	0.12 (5.86)			
Education				
HS graduate	-0.07 (6.09)			
Some college	-0.28 (5.58)			
College graduate	-0.41 (5.89)			
Post-graduate	**-0.45 (6.88)***			
BMI		0.20 (0.16)		
SBP		0.22 (0.10)		**.22 (0.07)****
DBP		0.03 (0.14)		
Comorbidity		0.09 (4.21)		
Social Support			0.02 (0.24)	
Depressive				

Symptoms			**0.47 (0.23)*** **	**1.11 (0.21)*** **
SSE_SRE			0.11 (0.11)	
Constant	50.15 (10.77)	2.91(13.19)	28.26(8.06))	3.55(10.32)

KEY: HS graduate-High school graduate; SBP-systolic blood pressure, DBP-diastolic blood pressure.

***denotes significance at .05 level, **denotes significance at .01 level, ***denotes significance *at <.01**

Table 3.6: Multivariable Linear Regression Results for Resilient Coping with final predictors

Variables β (se)	**Model 1 F=4.12($_{df}$81)**	**Model 2 F=1.80($_{df}$82)**	**Model 3 F=10.86 ($_{df}$83)**	**Model 4 F=25.34($_{df}$81)**
Age	.16 (0.12)			
Income				
$12K-$24K	0.02(0.83)			
$24K-$48K	**0.31(0.03)***			
$48K-$96K	**0.52(>.01)*****			
>$96K	**0.27(0.03)***			
Education				**2.18 (0.55)*****
HS graduate				
Some college				
College graduate				
Post-graduate				
BMI		-0.17 (0.13)		
SBP		0.13 (0.33)		
DBP		0.04 (0.77)		
Comorbidity		-0.14 (0.26)		
Social Support			0.14(0.13)	
Depressive Symptoms			**-0.50(0.13)*****	**-0.57 (0.11)*****
SSE_SRE			0.10 (0.06)	
Constant	16.89 (5.46)	24.41(7.52)	26.87(4.34)	23.52(2.64)

KEY: HS graduate-High school; SBP-systolic blood pressure, DBP-diastolic blood pressure;

Chapter 4

The Associations Between Illness Perceptions, Resilient Coping, and Medication Adherence in Young Adult Hypertensive African American Women.

Introduction

The global burden of hypertension (HTN) is estimated to affect over 1 billion people worldwide and nearly 100 million Americans with no evidence of those figures decreasing.[1,81] HTN is a modifiable precursor for the development of cardiovascular disease (CVD), which remains the number one cause of death both in the United States and globally.[138] Direct and indirect expenditures for CVD and stroke are estimated to total more than $329 billion dollars.[138] The new categorization of the American College of Cardiology and American Heart Association's (ACC/AHA) blood pressure (BP) [139] guidelines projects that more than half of the US adult Black or African American (AA) population will be reclassified as hypertensive.[81] Across racial ethnic groups, the prevalence of HTN was highest among non-Hispanic Black women (39.9%) compared to

non-Hispanic White women (25.6%).[140] More disturbing, Blacks or AAs 18-49 years are twice as likely to die from HTN, and those 35-64 years are 50% more likely to have HTN, compared to Whites.[7] The addition of lifestyle changes, including BP therapy, is imperative in order to attain BP control. Mounting evidence indicates that AAs develop HTN at younger ages, are less adherent, and more resistant to treatment.[5,12]

Over 50% of persons diagnosed with HTN are not controlled.[140] Unlike other illness conditions associated with a symptomatology, HTN is considered an asymptomatic condition, which poses a significant barrier in attaining both medication adherence and optimal BP control.[23] According to the Common Sense Model of Illness Perceptions (CSM),[25] illness representations are created and initiated by somatic sensations and deviations from normal function, observation and discussion of illness in others, and other external stimuli. Operationalizing HTN as a serious health threat without the presence of symptoms could be a potential cause of the growing racial HTN disparities.

Non-adherence to BP medication is considered a major contributor of uncontrolled HTN in AAs and younger AA women.[5,15] Reported barriers contributing to non-adherence in this age group have ranged from both isolated and multidimensional factors deriving from patient, health-system, therapy, condition, and social/economic categories.[84] Socio-demographic covariates including race, gender, age, and income have been considered to have an inconsistent relationship with medication adherence;[43,141] however, some studies have identified significant associations among these demographic covariates and BP medication adherence.[8,17]

HTN beliefs

HTN beliefs are another complex patient-related dimension strongly associated with BP medication adherence. HTN beliefs are neither common nor unique to one specific ethnic-racial group; however, AAs tend to view the etiological cause of HTN very differently when compared to other racial groups.[27,98] In AAs, HTN has been suggested to be a stress-related illness caused by the inequities of treatment deriving from racism and discrimination.[18,27] Further, the underlying belief that all AAs will develop HTN at some point during the life course makes recognition of the benefits in implementing lifestyle changes especially challenging.[27] Such beliefs have been examined and reported among hypertensive AAs in a study by Hekler, et al.[28] who described the relationship of adverse life stressors as contributing to ineffective self-management behaviors for HTN. These reported beliefs create a cumbersome barrier for medical providers to dismantle in order to achieve and promote overall positive cardiovascular outcomes. The perceived chronicity of HTN is also suggested to determine if an individual will initiate and adhere to BP medications. Acknowledgement of an illness condition that is typically not associated with somatic symptoms is arduous.[27] AAs diagnosed with HTN who report symptoms are suggested to have variable medication practices, suggesting the presence of symptoms is due to a temporal disease state.[5] When there are no symptoms, there is a greater propensity for medications to not be taken consistently or at all. The inconsistent practice of medication adherence increases the risk for development of a hypertensive emergency or crisis which is associated with symptoms of dizziness or headache.[98] Nonetheless, recognition and addressing of these beliefs by clinicians are important in order to prevent morbidity and other potential fatal complications including stroke as a result of uncontrolled HTN in an already high-risk population.

Resilient Coping

The importance and recognition of psychosocial factors and their relationship with BP medication adherence is garnering increased attention. Psychosocial factors, such as depressive symptoms, have been studied extensively across a variety of chronic illness conditions and their effect on health outcomes.[142] Unlike depression, the role of resilient coping is not clearly understood, particularly for its protective behavioral effect in the presence of adverse stress and health outcomes.[30,31] The concept of resilience, which derives from early locus of control studies, is a dynamic developmental process encompassing the ability to bounce back, overcome, and achieve a positive sense of well-being despite exposure to adverse circumstances and situations.[30,31] The need to understand the role and effect of resilient coping as a potential buffer from adverse stressors in addition to an important behavioral quality in hypertensive AA women may help to facilitate and increase an important health behavior. Along with the stressors of racial and gender discrimination, residence in disadvantaged neighborhoods, wage inequity, and lower social status/structural disadvantage, AA women are also faced with stressors of gender and role expectations within their families and work place.[51,116] Collectively, these stressors are believed to be an integral contributor of the racial health disparities in AA women. Although AAs are subjected to early and persistent life-adverse stressors, some AAs actually avoid ill health, negative well-being, and maladaptive coping behaviors to achieve positive health.[38,39,143] Mechanisms that underlie and could potentially explain the distinguishing characteristics of this group have not been well studied.

Socioeconomic Status

Internal wisdom would make the presumption that socioeconomic status (SES) would be an accurate predictor of treatment adherence. This covariate, however, has

yielded inconsistent findings.[43,141] One reason that may explain this relationship could be due to the unstandardized method that researchers implement to capture SES. A meta-analysis reviewing SES as a predictor of adherence identified various measures of how SES was captured, ranging from prescription drug coverage, income, education, employment, and household composition.[141] Nonetheless, some findings were not able to show evidence of a statistically significant relationship between income and medication adherence. A study examining medication routines and adherence among a sample of hypertensive AA participants found no statistically significant relationship between medication adherence and income.[8] Interestingly, over 60% of the sample reported an income less than $20,000 per year. A study examining predictors of medication adherence among a hypertensive AA sample also did not find any relationship between income and adherence.[61] Similar to the aforementioned study, the majority of the participants enrolled in this study reported an income range of $10,000-$20,000 per year. Interestingly, there was a gender by education level interaction identified among the study's participants. Low-educated (< high school) men and higher-educated (high school or above) women demonstrated better adherence compared to higher-educated men and lower-educated women.[61] Potential explanations for this relationship in women could be due to the notion that higher educated women had better health literacy and more financial resources, which makes medication affordability less cumbersome. The relationship in low-educated men regarding better adherence could be explained by the existence of a trusting patient-provider relationship, while higher-educated men's intellect could serve as a barrier by prohibiting the operationalization of a condition that tends to be absent of symptoms thus eliminating the benefit or need for medication. These rationales are mere

speculation based upon the current evidence supporting barriers to medication adherence. Nonetheless, these findings are unique, considering the relationship of lower SES being associated with suboptimal adherent behaviors and poor health outcomes.[141] These findings underlie the premise that low SES is not an automatic predictor of poor medication adherence or poor health outcomes,[15,133] further revealing the complex and interrelated factors underlying medication adherence and other important self-management behaviors.

Conceptual Model

Components from both the CSM[23] and the Transactional Model of Stress and Coping (TMSC)[72] will be used to answer the aims of this study (See figure 1). The CSM proposes that individuals create mental representations of their illness based on concrete and abstract sources of information (ex. family, friends, social environment, medical providers) in order to make sense of and manage their diagnosis.[25] These internal and external stimuli combine to formulate the type of coping response that will be used to engage and manage the stressor. This bi-directional relationship is constantly being appraised based on the outcome obtained.[23,25] Illness representations are comprised of the following five dimensions: *Identity* (label or name associated and perceptions of associated symptoms/conditions), *Cause* (beliefs of what caused the illness), *Timeline* (beliefs associated with disease/illness onset, duration, and decline), *Consequences* (anticipated effects the illness will have on an individual's life: physical, cognitive, social disruption), and *Cure/Controllability* (cure vs. control; self vs. medical provider).[25] Additionally, these mental illness representations influence how individuals will cope with the health threat, which will further influence the health behavior. For instance, if HTN is perceived as a long-term condition with serious consequences if not

properly managed, there is a greater likelihood the benefit of taking prescribed medications will outweigh the perceived risks, limiting concerns of potential medication side effects and increasing adherence.

Underlying possible contributors of poor-to-varying BP medication adherence including HTN beliefs, unique psychosocial factors, and coping responses have not been sufficiently studied among young adult hypertensive AA women.[15,17] Various interventions have been implemented to improve medication adherence[144] but a major obstacle preventing the success of interventions to enhance BP medication adherence, thus BP control, is lack of understanding of the complex and interacting dynamics of patient-level factors, such as HTN beliefs, sociocultural context, and mental well-being. Collectively, these circumstances make it difficult to develop targeted and effective interventions.[15] The primary aim of this study is to examine the effects that HTN illness perceptions and resilient coping have on BP medication adherence in AA women while controlling for sociodemographic and clinical factors. The following hypotheses will be tested: 1) Greater HTN illness perceptions are associated with increased BP medication adherence controlling for sociodemographic and clinical factors; 2) Greater HTN illness perceptions are associated with increased resilient coping and BP medication adherence; and 3) Greater resilient coping is associated with increased BP medication adherence. The exploratory aim for this study is to explore the relationship of resilient coping as a potential moderator of high or low adverse stress exposure with HTN medication adherence controlling for depressive symptoms.

Methods

The present study, embedded in a larger observational cross-sectional study, examines data on BP medication adherence among a sample of hypertensive Black

women 18-45 years of age. Women were eligible to participate if: they were at least 18 years, were born in the United States, identify as Black or AA by race, received a medical diagnosis of HTN from a clinician, were prescribed at least one BP lowering medication, and comprehend written and spoken English. Exclusion criteria include: non-Black or AA race, younger than 18 years or older than 45 years, non-English speaking, severe learning or cognitive disabilities, and pregnancy. Participants were recruited from community health screenings and cardiology and internal medicine ambulatory clinics. Institutional review board (IRB) approval for this study was received from Emory University and Grady Health IRB. Participants completed and signed informed consent.

Measures

The following variables measured for this study include: socio-demographic (age, education, income, health insurance), clinical (blood pressure, BMI, weight, comorbidities), cultural context (stress exposure), psychosocial (social support, depressive symptoms), and cognitive and behavioral (HTN illness perceptions and resilient coping) factors. Demographic and study questionnaires were completed via iPad, with paper forms utilized as a backup in the event of no Internet access.

Blood Pressure, Lipids, Demographics

All participants rested in a seated position with both feet flat on the floor for at least five minutes prior to having their BP measured. BP measurements were obtained using the automated Omron 10 series machine. The average of three BPs was taken at least 30 seconds apart and recorded. Lipid testing was done using the Cardiochek PA

analyzer. Demographic data, including height and weight, was obtained via self-report or review of the medical record.

Medication Adherence

The *Adherence to Refills and Medication Scale* (ARMS-7) assesses medication taking behavior and medication refills. The scale consists of seven items used to measure adherence, which is the outcome variable of this study. The instrument was developed utilizing a hypertensive minority patient population in a large urban medical center and has been well-validated with a demonstrated Cronbach's alpha ranging from 0.81-0.82.[77] The Cronbach's alpha value for this study is 0.75. The total scale score ranges from 7-25 and is obtained by taking the sum of all seven items. Scores can be interpreted as either continuous or dichotomized based on the instruments cutpoint score of 'seven' indicating perfect adherence or higher suggestive of some degree of non-adherence.[77] The Cronbach's alpha value for this study is 0.75. The score range for this instrument is 7-25.

Hypertension Illness Perceptions

The *Brief Illness Perception Questionnaire* (BIPQ) is an eight-item Likert-type scale assessing the dimensions of HTN, including: consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and illness concern.[74] Item nine of the BIPQ assesses the causal dimension of HTN where respondents can enter up to three causes of their HTN. Responses from this question were categorized by themes and analyzed. A total scale score was obtained by computing the mean across all items. In addition, each dimension was entered into the model to examine its association with medication adherence. A sample question from this scale reads, "How much does your high blood pressure affect your life?" The Cronbach's alpha

value for this scale ranges between 0.87-0.90.[74] The Cronbach's alpha value of the composite score for this study is 0.68. The Cronbach's alpha value of the composite score for this study is 0.68.

Resilient Coping

The *Connor-Davidson Resilience Scale* (CD-RISC 10) was used to measure resilient coping. The CD-RISC 10 is a 10-item scale that measures resilience, a multidimensional characteristic that varies based on context, gender, age, cultural origin, and age.[73] The CD-RISC 10 is one of two brief versions of the resilience scale comprising of items from the original CD-RSIC 25 item scale.[73] Scoring of the scale is additive and ranges from 0-40, with higher scores indicative of greater resilience. The CD-RISC has been well validated with a Cronbach's alpha value of 0.85.[33] The Cronbach's alpha value of the scale for this study is 0.89.

Depressive Symptoms

The *Patient Health Questionnaire (PHQ-8)* is a diagnostic and screening tool for depressive symptoms. The PHQ-8 was adapted from the PHQ-9 and does not contain the self-harm question. The score range for the PHQ-8 is 0-3, with a maximum score of 24.[128] The Cronbach's alpha value for the scale is 0.86 and the instrument has been validated and used across a variety of illness populations.[129,128] As a screening tool, a score of 10-14 is considered to be indicative of moderate depressive symptoms.[128] The Cronbach's alpha value of the tool for this study is 0.89.

Data Analysis

Data analysis was performed using STATA version 15.1 for MAC (College Station, TX) with a significant alpha value set at $p < .05$. Study data were collected and managed

using REDCap electronic data capture tools hosted at Emory University. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. Initial data analysis included descriptive statistics and examination of data to determine if assumptions for statistical test have been met.

Adherence was dichotomized based on a cut-point score of seven to reflect adherence and eight or higher as non-adherence. Bivariate associations of covariates and independent variables of HTN illness perceptions (composite score and individual dimension were tested separately) and resilient coping were used to identify which variables were significantly associated with HTN medication adherence. HTN illness perceptions and resilient coping will be examined separately using simple logistic regression and together via multivariate logistic regression as a predictor of medication adherence. Utilizing sequential regression blocks and stepwise variable selection methods within blocks, variables will be entered into the model and optimally selected. Interpretation of the data will hinge on the significance and the hypothesized direction of the relationships. Moderation will be tested to determine if resilient coping moderates the relationship between high and low stress exposure and medication adherence.

Results

The women in this study (N=85) were AA or Black and self-reported a current diagnosis of HTN and taking a prescribed BP medication. The women were 39.2 ± 5.4

years of age on average, with a BMI of 35.5 ±8.9. The majority of the women were insured (94%), single, had some college education, and were non-adherent as determined by their ARMS-7 scores. Demographic and physiological characteristics of the sample are presented in table 4.2. HTN beliefs scale by each dimension and adherent group are also presented in table 4.3.

Bivariate Analysis

Pearson correlation was used to examine the relationship among covariates and predictor variables of medication adherence (table 4.4). Medication adherence was correlated with BP (r=-24, p=<.03) and income (r=.25, p=.02) covariates. Adherence did not correlate with the composite score for the BIPQ scale so each item from the scale was entered separately. The *'Consequence'* (r=-.26, p=.01) and *'Identity'* (r=-.26, p=.02) were dimensions inversely correlated with medication adherence. Neither of the predictor variables were associated with medication adherence.

Regression Analysis

A simple logistic regression was performed to examine the relationship of BP, income, HTN beliefs composite score, '*Consequence*', and 'Identity' dimensions of the HTN beliefs scale separately (Table 4.1). A significant relationship was found between systolic BP (SBP) and medication adherence. Examination of the regression model between SBP and medication adherence revealed that for each one-unit increase in SBP, the odds of adherence decreased by 0.96. Upon further examination of the predictive margins, the odds of medication adherence decrease as SBP increases (see figure 4.1). Although there were no statistically significant relationships between the income categories and medication adherence, those whose income is >$96,000 per year did approach significance (p.05, CI=-.03-4.63). A statistically significant relationship was

evident between medication adherence and the '*Consequence*' dimension item (ipq_1) of the HTN illness beliefs subscale. For each additional increase in the 'consequences associated with HTN' dimension scores, the odds of medication adherence decreased by 0.78. Examination of the predictive margins indicates higher or greater perceived consequences associated with HTN increased the likelihood of non-adherence substantially (figure 2). Similar to the '*Consequence*' dimension, the '*Identity*' dimension (ipq_5) of the HTN beliefs scale and medication adherence was statistically significant, indicating for each additional increase in the '*Identity*' dimension, the odds of adherence decreased by 0.76 (figure 3). A multivariate logistic regression model was tested with adherence as the outcome and the significant covariate of BP, in addition to, '*Consequence*' and '*Identity*' dimensions, HTN beliefs, and resilient coping. The following independent variables were entered into the model for their association with medication adherence: composite score of HTN illness perceptions, the '*Consequence*' and '*Identity*' dimensions of the HTN illness perception scale, and resilient coping, neither dimension was no longer significant in the model (table 4.5.) Using stepwise logistic regression with forward variable selection, SBP, '*Consequence*' and '*Identity*' dimensions, income, education, HTN beliefs composite score, and resilient coping were tested for entrance into the model, respective to their relationship with adherence (table 4.6). The '*Consequence*' dimension, resilient coping, and SBP were the remaining significant variables of the model (χ^2=17.02, p=<.01). Using the same approach, the three variables were re-examined collectively for their effect on medication adherence. Decreased SBP and lower scores of the '*Consequence*' dimension were the only two significant remaining variables (χ^2=10.53, p=.001).

Moderation Analysis

The main effects and interaction were tested to determine if resilient coping moderates the relationship between adverse stress exposure and medication adherence (table 4.7). There was no evidence of a statistically significant relationship (z=1.14, p=0.25) (figure 4). However, upon closer examination of the predictive margins, resilient coping scores within the range of 29-38 and in conjunction with exposure to adverse social stressors (scores 22-30) were significant. Controlling for demographic covariates (table 4.8), the interaction remained non-significant (z=0.05, p=0.59), but those in income categories of more than $96,000 per year did have a statistically significant relationship with adherence. Controlling for clinical covariates (table 4.9), the interaction was not significant; however, SBP was the only remaining significant variable in both the MLR and moderation models. Controlling for depressive symptoms, the interaction remained non-significant, while neither of the predictor variables had a significant effect on medication adherence.

Adverse stress exposure and the composite score for HTN beliefs, in addition to the '*Consequence*' and '*Identity*' dimensions were entered separately to test for differences in resilient coping scores. There were no statistically significant differences in any of the moderation analysis examined (figures 4-7). There were no significant differences between resilient coping and adverse stress exposure. Examination of the predictive margins for the relationship between HTN beliefs and resilient coping with medication adherence as the outcome indicates a significant relationship between those with a score of seven on the HTN beliefs and 28 on resilient coping. The '*Consequence*' and '*Identity*' dimensions of the HTN beliefs scale demonstrated a significant relationship with resilient coping only in the MLR model without moderation (table 4.10). The relationship was no longer significant in the moderation model. The

predictive margins for both dimensions were significant for resilient coping scores within the range of 20-38 and an illness perception score of 1, although the interaction model was not significant.

Discussion

The goal of this study was to examine the relationships of HTN beliefs and resilient coping in addition to the clinical and demographic covariates with medication adherence. Of the study sample, nearly 70% of the participants were found to be non-adherent to their BP medications. This number is close to the reported range of non-adherence among hypertensive populations, which is reported higher in Blacks or AAs and Asians.[145]

The study findings did not support any of the study's hypotheses. The findings from this study did not find any significant relationships between adherence and HTN illness perceptions or resilient coping. However, adherence was associated with the 'Consequence' and 'Identity' dimensions of HTN illness perceptions despite the direction of these relationships. Specifically, possessing a more threatening perception of the 'consequences' and 'identity' dimensions of HTN illness perceptions were associated with decreased adherence. Although this finding supports the presuppositions underlying both the CSM and TMSC, which posits that possessing a more threatening perception of an illness affects health outcomes and coping,[25,146] adherence was actually decreased instead of increased. Beyond the scope of this study, medication side effects or ineffective treatment may have impacted the perception surrounding the 'Consequence' and 'Identity' dimensions of HTN illness perceptions. Specifically, if participants are experiencing symptoms and also have uncontrolled BP regardless of demonstrating medication adherence, there is a strong likelihood for these

dimensions to be adversely perceived. Conversely, if side effects were an issue, these could also potentially impact the perceived 'Consequences' the women may have been experiencing. This is mere speculation, as side effects were not examined in this study. Findings did demonstrate that SBP was the only clinical covariate associated with adherence. The dimensions of '*Consequences*' and '*Identity*' were associated with medication adherence. The mean SBP of adherent (129±13) versus non-adherent (139±15) patients was lower and reached significance. Although there was a significant difference between the groups, SBP was still elevated, according to the new 2017 American College of Cardiology/American Heart Association Blood Pressure guidelines.[80] Without being able to assess the participant's baseline BP prior to initiating therapy, the author's cannot conclude the efficacy of the prescribed medication regimen. There were no observed differences between the diastolic BP between the two groups. Previous studies have reported a correlation of SBP control and medication adherence.[8,147] Other studies examining illness beliefs did not report any association between beliefs and treatment outcomes.[29,147,148]

Income was examined for its association with adherence. Specifically, those who made $96,000 per year or more had a significant relationship with adherence. SES has been considered an inconsistent predictor of treatment adherence;[8] however, our findings did show a significant relationship between higher income and adherence. Despite this finding, care must go into interpretation due to the small sample size and should be tested in a larger sample to examine if this effect persists.

Finally, the results of the study's exploratory aim which explored the relationship of resilient coping as a potential moderator of high or low adverse stress exposure and its effect on BP medication adherence, did not demonstrate any statistically significant

models. Upon further examination of the predictive margins for the predictor variables with resilient coping however, did yield significant relationships. A less threatening perception of HTN beliefs in the '*Consequence*' and '*Identity*' domains of the scale demonstrated a significant relationship with resilient coping relative to higher resilient coping scores, and a less threatening perception of HTN associated with '*Consequence*' and '*Identity*' dimensions. This relationship suggests increased or greater resilient coping serves as a buffer in the presence of HTN attenuating the illness perceptions surrounding the consequences and symptomatology of HTN. This relationship could be the evidence of actively seeking and implementing a problem-focused coping style which allows for increased coping processes that may serve in adjusting and living with HTN. If an individual perceives an obstacle as one they are able to overcome, then the obstacle does not present as a strong threat. In this case, HTN is the threat, but possessing resilient coping has diminished the negative effects of the illness. However, the coping relationship did not have any effect on medication adherence.

The models in the study findings did not demonstrate resilient coping as a moderator of adverse stress exposure in relation to adherence. Adverse stress exposure was not associated with any of the demographic or clinical covariates, including the predictor variable of resilient coping. When this relationship was tested with resilient coping as the moderator and medication adherence as the outcome, there was no evidence to support changes in the slopes of the group. Upon closer examination of the predictive margins to better understand if some differences exist, it became apparent that discriminatory stressors were associated with decreased adherence in women with lower resilient coping scores. Women who possessed higher resilient coping scores also had better adherence indicating that resilient coping may serve as a buffer from the

adverse effects of discriminatory stressors. Further testing of this relationship with a larger sample will be needed to investigate if this interaction holds true. The causal dimension of the HTN beliefs scale allowed the participants to list up to three causes for their HTN and stress was the second most reported cause after dietary habits. The study did not examine nor define stress because many things could be attributed to its etiology. A study examining HTN control in AA females indicated that stress was found to be associated with higher SBP specifically among younger adult women.[137] HTN has long been perceived as an illness caused by stress among Blacks.[27]

There are several limitations that must be acknowledged. First, this study is a cross-sectional study and therefore, causal relationships cannot be determined. Though this is a limitation, the findings obtained can inform the direction for future studies examining such a complex topic. Second, the sample size of this study was not large enough to detect any interaction effects. Some of the relationships did approach significance but ultimately, there was not enough power to yield significant findings. Despite this imperfection, useful information could still be gleaned when examining the relationships of resilient coping, adverse stressors, and medication adherence. Third, the majority of the sample was categorized as non-adherent, leaving fewer adherent participants to be included in the statistical analysis. Although the proportion of 'adherent' versus 'non-adherent' participants in this study was low, these figures are considered reflective of the overall AA hypertensive population. The HTN illness perceptions scale's reliability for this study was moderate (.68) demonstrating there may be better measures for examining HTN beliefs especially in minority populations. Additionally, studies that have used this scale included populations that had a higher symptomatology such as rheumatoid arthritis, diabetes, and lung cancer so the illness

perceptions would tend to differ in relation to HTN. The ease of use and comprehension of this scale made administration less cumbersome, minimizing respondent fatigue. Self-report was used in gathering responses from the questionnaires, which could contribute to bias, and inaccurate responses. Finally, the results obtained from this study are not generalizable to the entire adult hypertensive population since this sample consisted of AA young adult women.

Conclusion

The results of this study highlight the importance of examining the role that HTN illness beliefs and resilient coping have on BP medication adherence. Recognizing that beliefs are multilayered and consists of a variety of stimulus sources, in addition to their influence on treatment outcomes may lead to better BP control and medication adherence. Clinicians may use the findings from this study to better counsel high-risk populations on the concerns they may have that could inhibit medication adherence and BP control. Although adverse stressors were not associated with adherence in this study, further examination of the definition of perceived stress and how it contributes to HTN, especially in AAs, is necessary. Future research is needed in larger population based studies to examine HTN beliefs and the role of resilient coping as a buffer in the presence of various stressors. If resilient coping is a positive factor in medication adherence, interventions to modify this amenable factor can be developed and tested for its effects. Gaining a better understanding of the role that resilience has in the presence of illness and adversity could significantly contribute to better-achieved health outcomes.

Table 4.1. Simple linear regression with Medication Adherence (ARMS-7)

Variables	**OR**	**SE**	***z***	**p**	**95% CI**
SBP	0.96	0.02	-2.16	0.03	0.92-0.99
Income	1.78	0.47	2.18	0.03	1.05-3.00
HTN beliefs	0.96	0.02	-1.72	0.09	0.92-1.01
'Consequence'	0.78	0.08	-2.35	0.02	0.64-0.96
'Identity'	0.76	0.09	-2.33	0.02	0.60—0.96

Key: SBP-Systolic blood pressure; HTN beliefs-hypertension beliefs composite score; 'Consequence' dimension of the HTN beliefs scale; 'Identity' dimension of the HTN beliefs scale.

Table 4.2. Demographic and Physiological Characteristics of Participants (N=85)

Characteristics	N(%)	Scale range
Demographics		
Age	39±5.4	24-45
Income		
Less than $12,000/year	15 (18.3)	
$12,000-$24,000/year	7 (8.5)	
$24,000-$48,000/year	30 (36.6)	
$48,000-$96,000/year	18 (22)	
$>$96,000/year	12 (14.6)	
Health Insurance		
Yes	79 (94)	
No	5 (6)	
Education		
9^{th}-12^{th} Grade	6 (7.1)	
HS Graduate	12 (14.3)	
Some College	26 (31)	
College Graduate	28 (33.3)	
Post-Graduate	12 (14.3)	
Marital status		
Yes	33 (39)	
No	52 (61)	
Clinical		
Comorbidities	12(14%)	

Systolic BP (mm Hg)	137.2±15.7	106-168
Diastolic BP (mm Hg)	88.8±12.1	56-127
BMI	35±8.9	20.4-67.9
Weight (lbs)	213.5±55	122.4-411
Cholesterol		
Total Cholesterol	176.4±37.3	96-259
HDL	53±15.2	12-95
LDL	100±41	31-282
Measures		
Adherent		
Yes	16(18.8)	
No	69(81.2)	
Adherence (ARMS-7)	11.5±3.9	7-25
Illness Perception (BIPQ)	41±12.6	7-68
Resilient Coping (CDRISC-10)	29.1±7	12-40
Depressive Symptoms (PHQ-8)	6.4±5.6	0-24
Lifetime Racial & Gender Discrimination Events (SSE_SRE)	42.1±12.3	22-72

Key: BMI-body mass index; BP-systolic blood pressure

Table 4.3. HTN illness Beliefs score dimensions (means and standard deviations) compared between adherent and non-adherent hypertensive African American women. Sample (n=85)

HTN illness beliefs dimensions	**Mean ± SD**	
	Adherent	**Non-Adherent**
IPQ1-Consequence	4.3±3.0	6.3±2.8
IPQ2-Timeline	5.9±3.3	5.8±3.7
IPQ3-Personal Control	4.2±2.9	4.2±2.7
IPQ4-Treatment Control	1.9±1.4	2.9±2.2
IPQ5-Identity	3.8±2.6	5.6±2.7
IPQ6-Illness Concern	8.7±3.0	8.5±2.3
IPQ8-Coherence	1.9±1.6	2.8±2.4
IPQ8-Emotional Representation	5.3±3.0	6.0±3.3

KEY: IPQ (Illness perception questions)

Table 4.4. Bivariate Correlation of Medication Adherence

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Adh	-												
2. SBP	-0.24*	-											
3. Diast.	-0.10	0.55***	-										
4. Income	0.25*	-0.06	0.12	-									
5. Educ	0.13	0.01	0.09	0.65***	-								
6. Insured	0.12	-0.31***	-0.16	0.10	0.21	-							
7. Adverse stressors	-0.15	0.21	0.09	0.33***	0.23*	0.06	-						
8. Social support	0.21	-0.05	-0.04	0.08	0.03	0.03	-0.30**	-					
9. Illness beliefs	-0.19	0.26*	0.16	-0.24*	-0.36***	-0.32***	0.21	-0.15	-				
10.							-		-				

Resilient Coping	0.14	0.11	0.12	0.36***	0.44***	0.15	0.05	0.26*	0.28**	-			
11. Depress	-0.14	-0.02	-0.12	-0.18	-0.16	-0.20	0.22*	-0.30**	0.49***	-0.52***	-		
12. Consq	-0.27*	0.14	0.03	-0.27*	-0.19	-0.27*	0.10	-0.06	0.59***	-0.05	0.24*	-	
13. Identity	-0.26*	0.18	0.01	-0.35**	-0.43***	-0.35**	0.06	-0.09	0.66***	-0.43***	0.34*	0.36***	-

KEY: *p<.05, **p<.01, ***p<.001. Abbreviations: Adh-Adherent category 0-no & 1-yes; SBP-Systolic Blood pressure; Diast-Diastolic Blood pressure; Educ-education; Depress-Depression; 'Consequence'-consequence dimension of the HTN illness perception questionnaire;'Identity'-identity dimension of the HTN illness perception questionnaire;

Table 4.5. Logistic Regression table for predictors of Medication Adherence

Source	**OR**	**SE**	**z-ratio**	**P-value**	**95% CI**
Hypertension Illness beliefs	1.03	.04	0.88	0.38	0.96-1.11
'Consequence'	0.77	.10	-1.91	0.06	0.59-1.01
'Identity'	0.77	.16	-1.57	0.12	0.56-1.07
Resilient coping	1.03	0.05	0.61	0.54	0.94-1.13
Constant	0.37	0.69	-0.54	0.59	0.01-14.60

Model χ^2=10.52 p- value 0.03
Pseudo R^2= 0.13
N= 85
***Medication adherence is the outcome variable and was coded 0 for nonadherent and 1 for adherence.**

Key: 'Consequence'-'consequence' dimension of the HTN illness beliefs scale, 'Identity'-'identity' dimension of the HTN illness beliefs scale.

Table 4.6 Forward Stepwise Logistic Regression Results for predictors of Adherence

	A	B
Constant	45.34 (154.72)	234.93 (679.87)
SBP	0.95* (0.02)	0.96* (0.02)
'Consequence'	0.77* (0.09)	0.79* (0.09)
Resilient Coping	1.11* (0.06)	
Chi square	17.02	10.53
p-value chi square	0.0007	0.0052
No. Observations	82	85

Standard errors are reported in parenthesis;*indicates significance at the 95% level, respectively.

Figure 4.1. Relationship between the predicted margins of systolic blood pressure and Medication Adherence

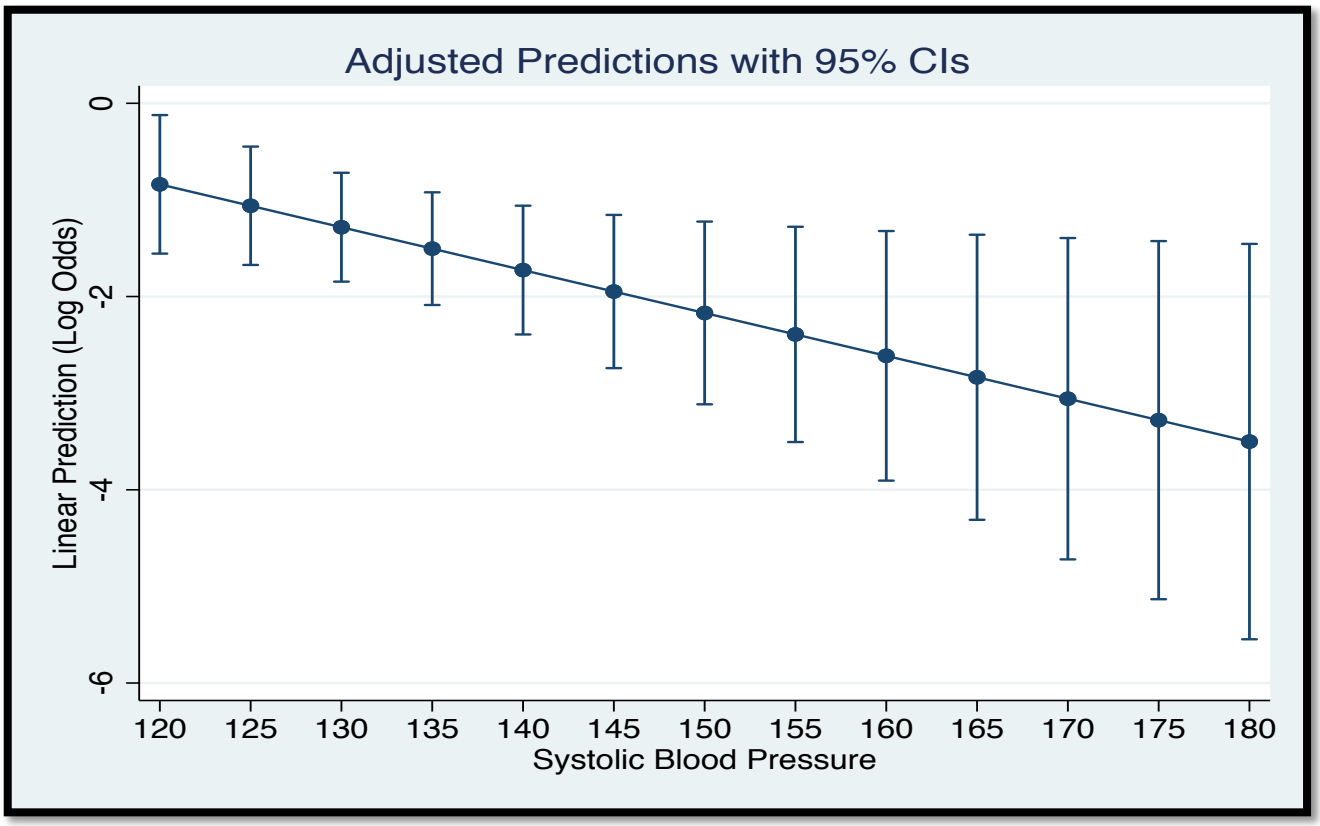


Figure 4.2. Relationship between Adherence and 'Consequence' dimension of the HTN beliefs scale

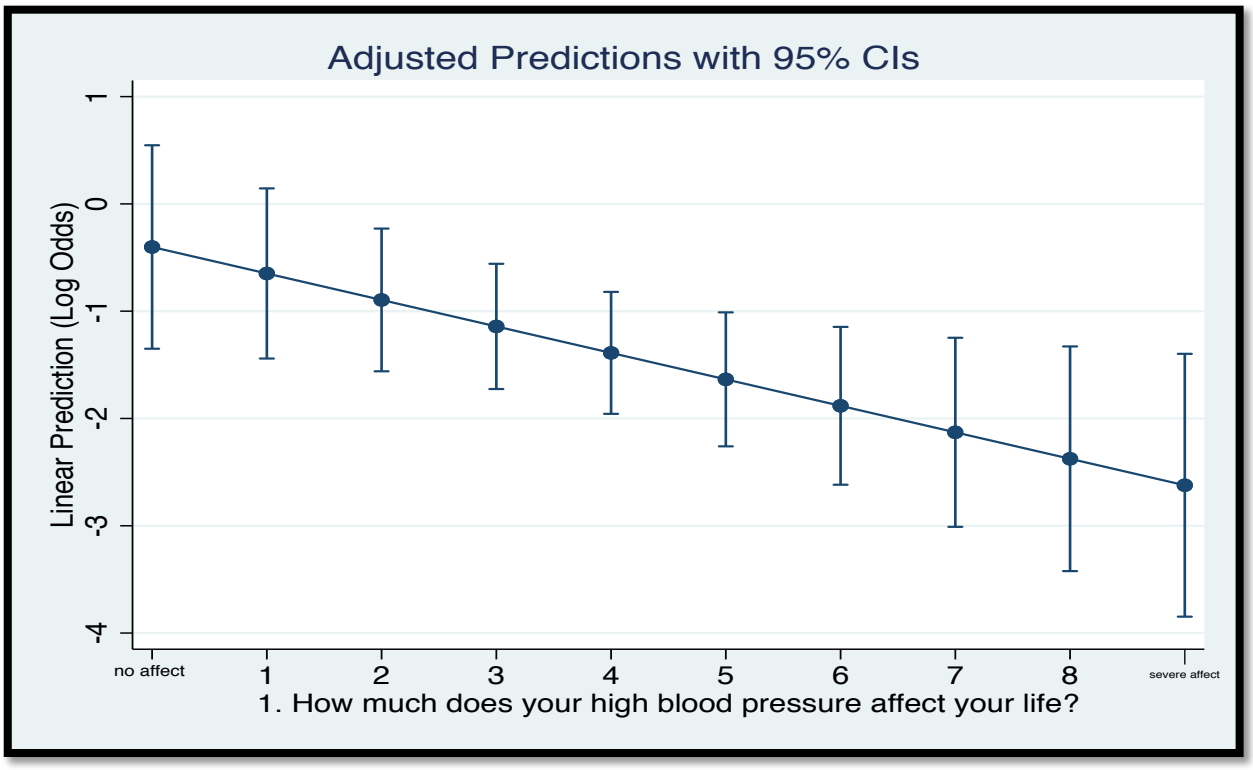


Figure 4.3. Relationship between Adherence and 'Identity' Dimension of the HTN beliefs Scale.

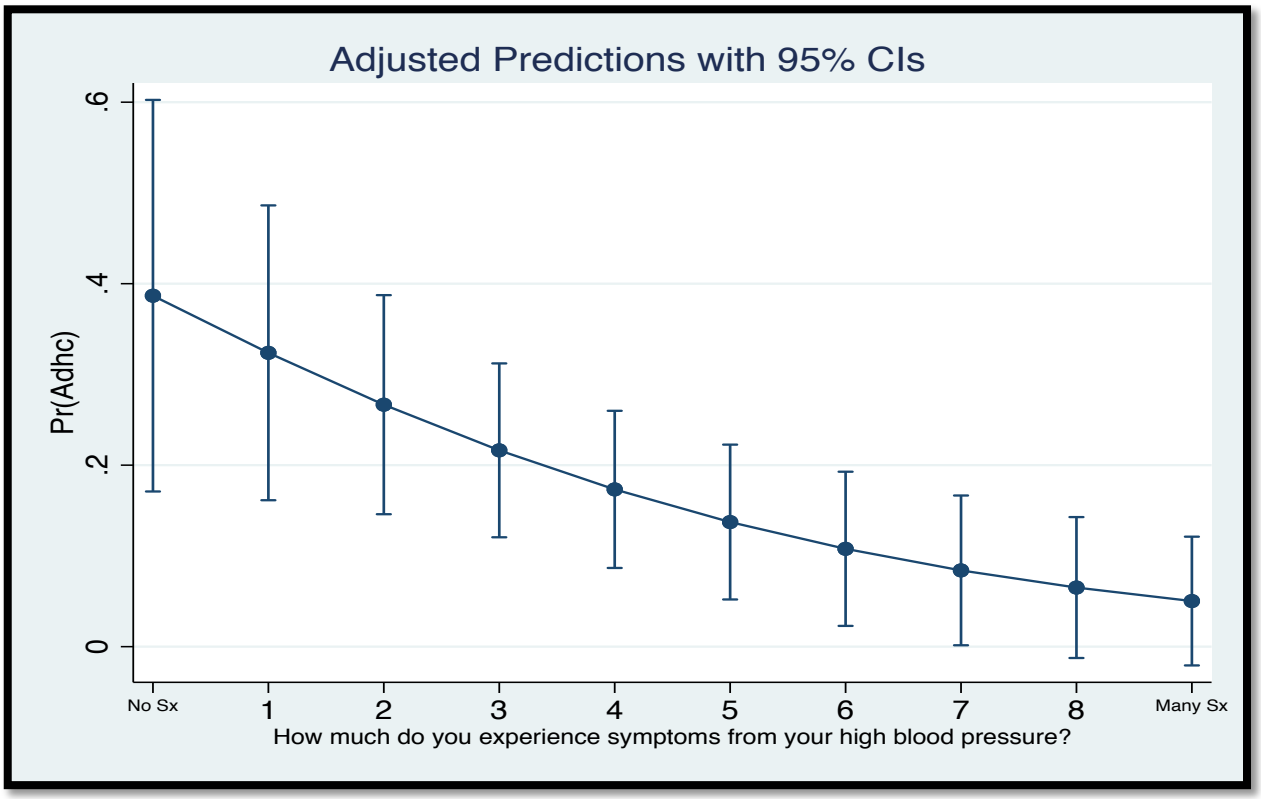


Figure 4.4. Slopes analysis between resilient coping and adverse stress exposure

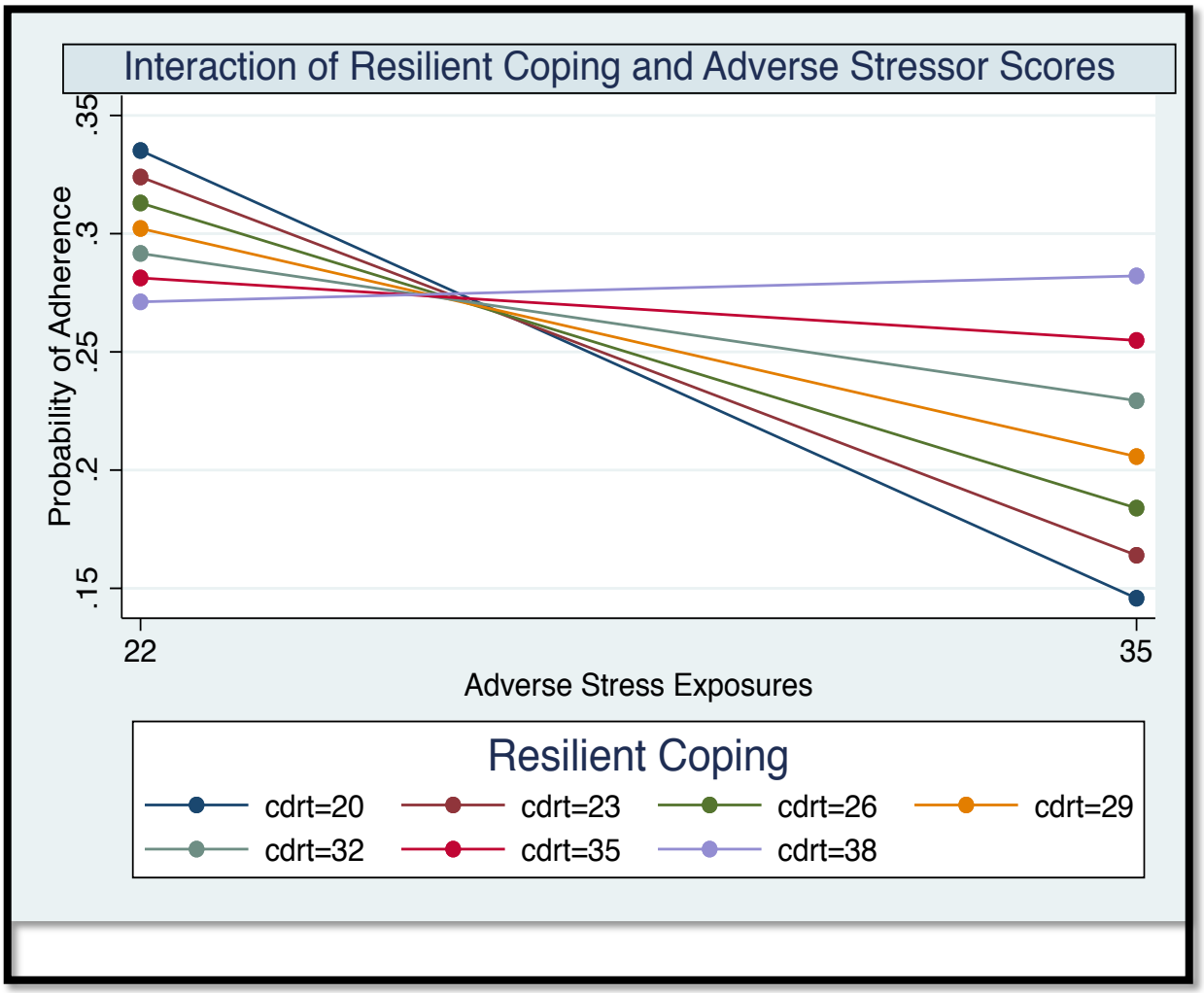


Figure 4.5. Slopes analysis between resilient coping and HTN beliefs

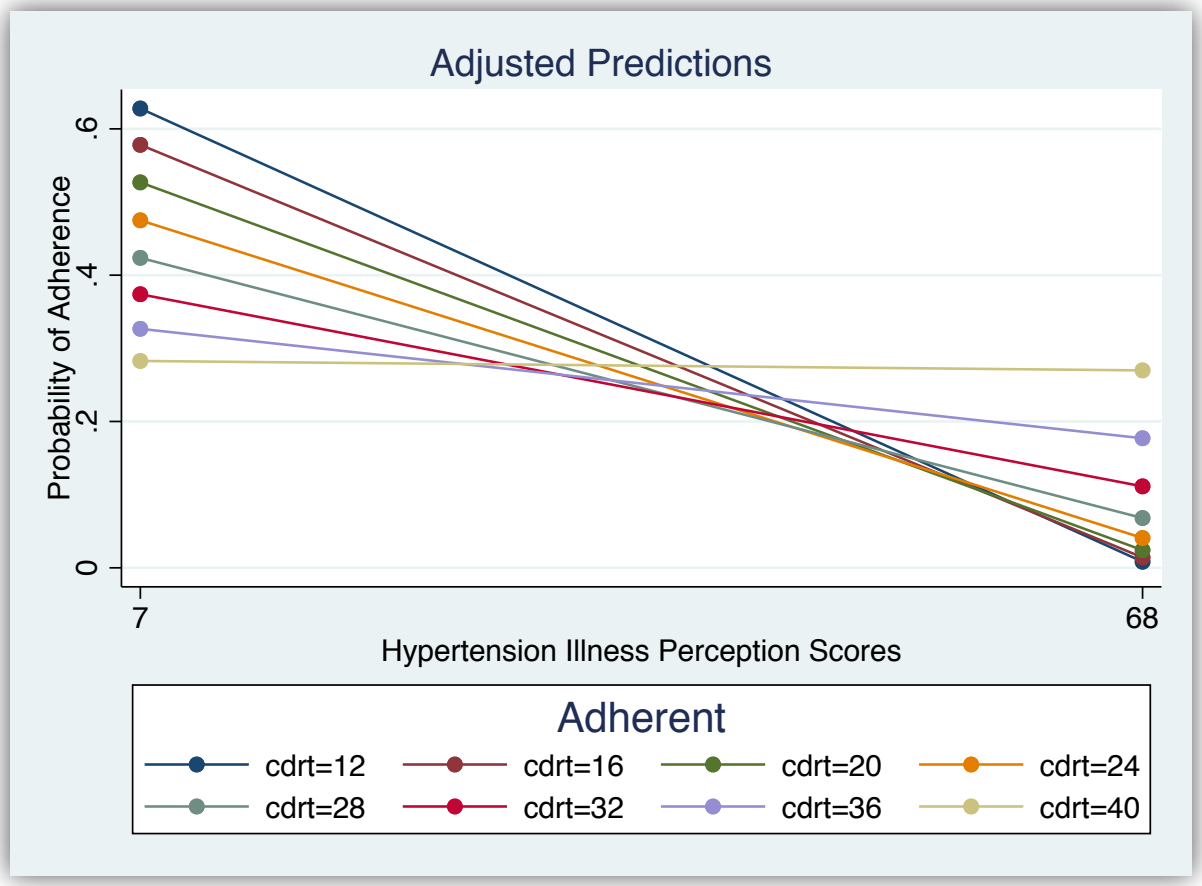

Adjusted Predictions
Probability of Adherence
0
.2
.4
.6
7
68
Hypertension Illness Perception Scores
Adherent
cdrt=12
cdrt=16
cdrt=20
cdrt=24
cdrt=28
cdrt=32
cdrt=36
cdrt=40

Figure 4.6. Slope analysis between resilient coping and 'Consequence' dimension

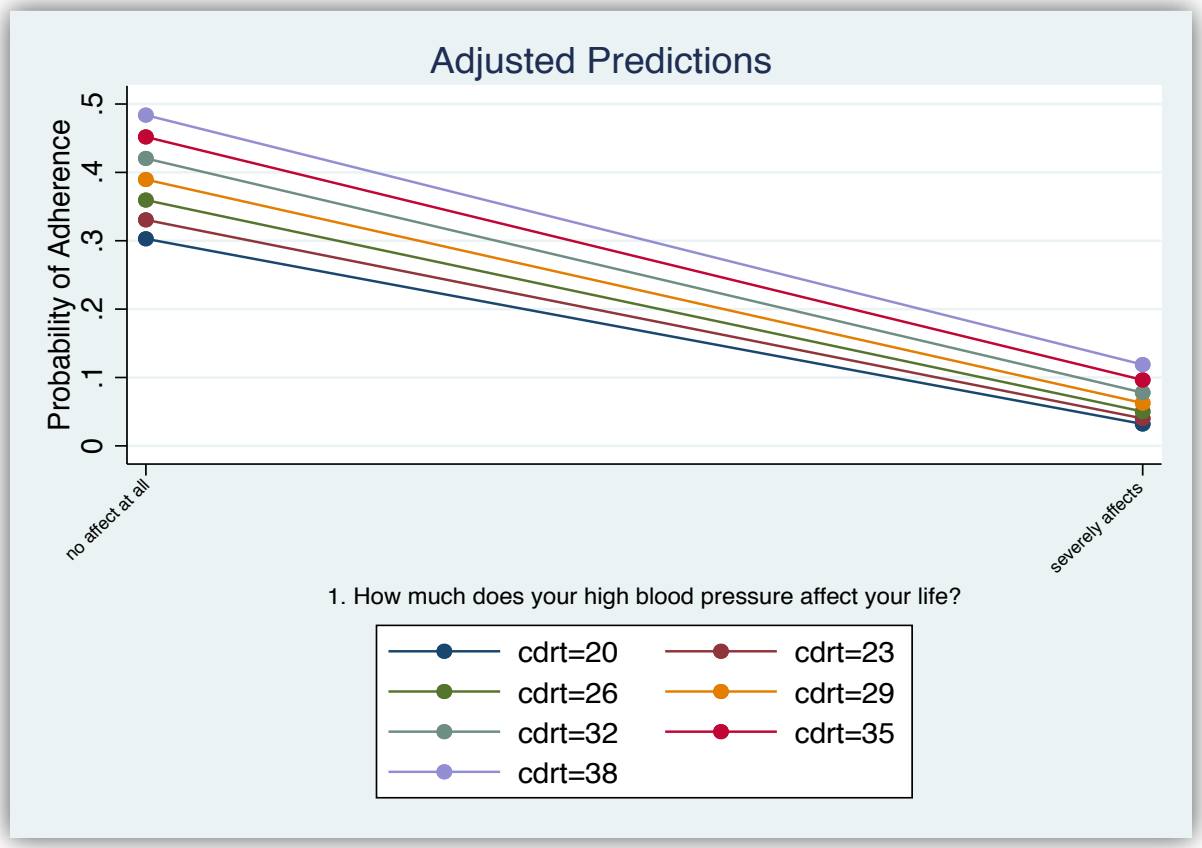
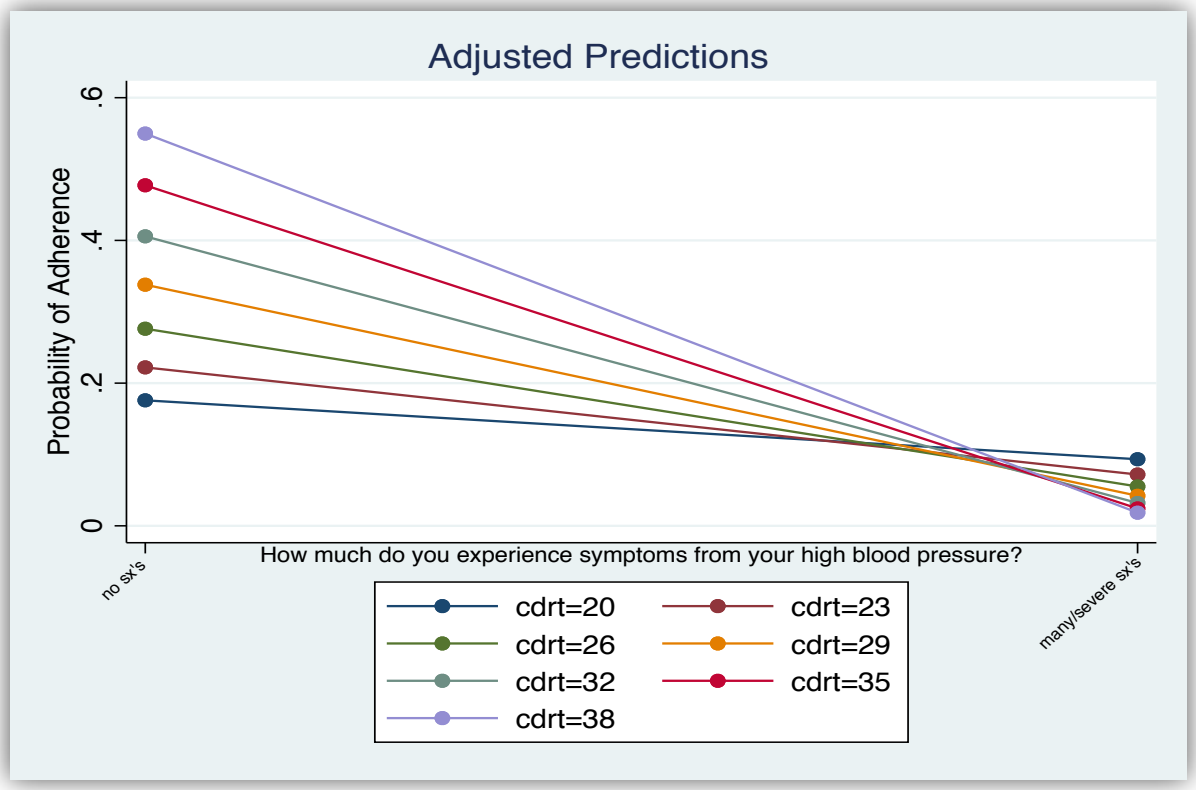


Figure 4.7. Slope analysis between resilient coping and 'Identity' dimension of the HTN beliefs scale



Chapter 5: Discussion and Conclusion

The purpose of this cross-sectional dissertation study was to examine the relationships between sociodemographics, psychosocial, behavioral, and cognitive factors with blood pressure (BP) medication adherence in African American (AA) women 18-45 years of age. The specific aims of this study were to: (1) Examine the effect that exposures to contextualized racial and gendered stressors, social support, and depressive symptoms have on hypertension (HTN) illness perceptions, resilient coping, and BP medication adherence; and (2) Examine the effects that HTN illness perceptions and resilient coping have on BP medication adherence in hypertensive AA women while controlling for sociodemographic and clinical factors. Additionally, there was an exploratory aim to examine the relationship of resilient coping as a potential moderator of high or low adverse stress exposure and its effect on BP medication adherence.

The World Health Organization defines medication adherence as "the degree to which a person's behavior corresponds with the agreed recommendations from a healthcare provider".[84] Medication adherence is a multidimensional behavior that is impacted by the following dimensions: *social and economic, healthcare system, condition-related, therapy-related, and patient-related*.[84] These factors contribute to medication-taking behaviors, including intentional (choosing not to take a medication[s]) or unintentional (meaning to take medications in the correct way but do not).[31,84,85] Medication nonadherence has important health implications that can range from a decreased quality of life to a poorly controlled disease process, or even death.[149] An estimated 50% of the worldwide population has a chronic condition.[150] Additionally, an estimated 50% are considered nonadherent to long-term therapy for chronic illness, which signals the pervasiveness of this modifiable health related issue.[150] Among AAs, the odds of non-adherence have been reported to range from 80% to as high as 330%.[26]

Poor adherence and nonadherence to hypertensive medications have been strongly indicated as a primary contributor to the early onset of disparity in cardiovascular disease (CVD) morbidity and mortality that is experienced by AAs.[8]

The economic impact of uncontrolled HTN in the United States, including costs designated for HTN treatment and morbidities, medications, and missed time from work, is estimated at $93.5 billion dollars per year.[110] A retrospective cohort study examining the economic burden of common chronic conditions, including HTN, revealed that patients diagnosed with HTN who were non-adherent and became adherent to their medications spent on average $766 less per year than those who remained non-adherent.[151] Consequentially, persons with HTN who were adherent, but later became non-adherent, spent $2,663 more,[151] revealing the economic burden and cost associated with disease progression as a result of uncontrolled HTN.

In 2016, across ethnic groups in the United States 20 years and older, AA women represented the highest prevalence of HTN (44%) compared to AA men (42.4%) and Whites (men 30.2% and women 28%), respectively.[3] Importantly, AA women have the highest death rates from heart disease, a complication of uncontrolled HTN.[6] Additionally, AAs 18-49 years old are twice as likely to die from heart disease as Whites, and AAs aged 35-64 are 50% more likely to have HTN compared to Whites.[7]

Barriers to achieving optimal BP medication adherence have been extensively characterized among AA women and include patient-level factors of: denial coping,[5,44] role demand (single parent, multiple jobs),[5] lack of a support system,[5,121] and adverse life stressors (poverty, gender and racial discrimination, living in disadvantaged neighborhoods),[5,18,43,44] which have also been associated with depressive symptoms;[5,43,44,123] however, these have not been fully examined in younger women.

Regardless of these barriers and irrespective to social class, some hypertensive AA women have demonstrated good BP medication adherence.[15] Underlying possible contributors of poor-to-varying BP medication adherence such as HTN beliefs, unique psychosocial factors, and coping response have not been sufficiently studied among this at-risk group.[12,97] This study sought to identify factors that enhance BP medication adherence between women who were adherent and non-adherent with their BP medication.

Summary of Research Findings

Each of the three papers (Chapters 2-4) included in this dissertation adds a unique contribution to the existing literature as it relates to BP medication adherence in AA women. Chapter 2 presents an in-depth literature review and synthesis, which leads to the hypothesis of relationships between HTN beliefs, psychosocial factors, resilient coping, and BP medication adherence. Chapter 3 presents findings related to Aim 1, which examines the effect that exposures to contextualized racial and gendered stressors, social support, and depressive symptoms have on HTN illness perceptions, resilient coping, and BP medication adherence. Chapter 4 presents findings related to both Aim 2 and the exploratory Aim, which examines the effects that HTN illness perceptions and resilient coping have on BP medication adherence in hypertensive AA women while controlling for sociodemographic and clinical factors, in addition to exploring the relationship of resilient coping as a potential moderator of high or low adverse stress exposure and its effect on BP medication adherence. Each of the chapters is discussed in more detail below.

Chapter 2

The first manuscript (Chapter 2) summarizes the current knowledge regarding the known and unknown contributors of BP medication adherence. The manuscript synthesizes the literature on the various factors that impact medication adherence in the five following dimensions: *social/economic, provider-patient/healthcare system, condition-related, therapy-related*, and *patient-related*. Due to the complex and multifactorial nature of medication adherence, this dissertation study will focus on the *patient-related* factors to better understand how these may potentially impact BP medication adherence in young AA women. The combination of the lived environment, psychosocial factors, and pre-existing experience with illness must be appreciated to better understand the various factors that impact medication adherence. The conceptual model introduced in this review used for hypothesis testing is adapted from two complementary health behavior change models, the Common Sense Model of Illness Representations (CSM) and the Transactional Model of Stress and Coping (TMSC). The premise of the CSM suggests that individuals create mental representations of their illness based on concrete and abstract sources of information available to make sense of and manage their illness.[25,72] Likewise, both models suggest that derived meaning from the information obtained and used to facilitate management of the illness, also informs the coping efforts, which are geared toward problem management and emotional regulation.[25] Chapter 2 of this dissertation details the concepts that were used to frame this study and include: psychosocial factors (depressive symptoms, racial and gendered stressors, social support), HTN illness perceptions (cognitive), resilient coping (behavioral), and BP medication adherence. Concentrating on these dimensions is

especially essential in order to have a better understanding of factors that may be important contributors to the growing racial HTN disparities.

Chapter 3

The second manuscript of this dissertation study (Chapter 3) presents findings from the analysis of Aim 1, which sought to examine the relationships of exposure to contextualized racial and gendered stressors, social support, and depressive symptoms with HTN illness perceptions, resilient coping, and BP medication adherence. Initial analyses were done to examine the relationship of stress exposure, social support, and depressive symptoms with BP medication adherence. The study hypothesis for Aim 1 was: decreased exposure to adverse stressors, increased social support, and fewer depressive symptoms are associated with greater HTN illness perceptions, greater resilient coping, and increased BP medication adherence. Adherence, the outcome variable, was dichotomized based on a cut-point score to reflect a score of seven equal to adherence and eight or higher as non-adherence.

Bivariate associations of demographic (age, income, education, health insurance) and clinical (BMI, systolic and diastolic blood pressure [BP], comorbidities) covariates and independent predictors of stress exposure, social support, and depressive symptoms were used to identify which variables were associated with medication adherence, HTN illness perceptions, and resilient coping. Variables that were identified to have a significant relationship with the outcome variables were entered into the regression model. Systolic BP (SBP) was the only clinical covariate that was associated with medication adherence ($r=-0.24$, $p=0.02$); higher SBP was associated with lower medication adherence. SBP was examined for differences between groups (adherent

versus nonadherent); there was a significant difference in the mean SBP between adherent (M=129.4, SD=13) and non-adherent (M=139.1, SD=15.8) t2.3(83), p=0.03. The composite score for the HTN beliefs scale was not associated with adherence. However, there was a statistically significant relationship between the mean scores of adherent versus nonadherent participants on the 'Consequence' (M=6.3, SD= 2.8 and M=4.3, SD=3; t2.51(83), p=0.01) and 'Identity' (M=5.6, SD=2.7 and M=3.8, SD=2.6; t2.5(83), p=0.02) dimensions of the HTN beliefs scale. Controlling for clinical and demographic covariates, income (OR=2.46, p=0.02) and SBP (OR=.95, p=0.05) were the only predictors of medication adherence, indicating the odds of adherence are 2.46 times greater in those with higher incomes, while the odds of adherence decreased by 0.95 for each 1-unit increase in SBP. Step-wise backward selection estimation procedure was performed to test for significant predictors of adherence. SBP was the only significant predictor remaining in the model (OR=0.95, p=0.02).

Bivariate analysis was performed for covariates and predictor variables that were associated with HTN illness perceptions and resilient coping. SBP (r=0.26, p=0.02), sociodemographic variables of income (r=-0.24, p=0.03), insured status (r=-0.32, p=<.01), and education (r=-0.36, p=<.001) were correlated with the HTN illness perceptions composite score. In model one of the multiple regression model, post-graduate education (β=-16.03, p=.02) was the only predictor of HTN illness perception. In model two, none of the clinical covariates were associated with HTN illness perceptions. In model three, increased depressive symptoms (β =1.07, p=<.001) were the only predictor of HTN illness perceptions. In the final model, higher SBP (β=0.22, p=<.01, R^2=0.31) and increased depressive symptoms (β=1.11, p=<.001) were the remaining two variables associated with HTN illness perceptions.

Income (r=0.36, p=<.001) and education (r=0.44, p<.001) were the only covariates associated with resilient coping. Social support (r=0.26, p=0.02) and depressive symptoms (r=-0.52, p=<.001,) were the only psychosocial variables associated with resilient coping. Higher income categories of $48,000-$96,000 (β=6.27, p=0.03) per year had a linear relationship with higher resilient coping and higher adherence. Education categories from 'some college through post-graduate' had a significant association with resilient coping. Neither of the clinical covariates had a linear relationship with resilient coping. Depressive symptoms (β=-.63, p=<.001) was the only psychosocial variable that had a significant relationship with resilient coping. Multiple regression analysis was performed to examine covariates as predictors of resilient coping. Decreased depressive symptoms (β=-0.57, p=<.01) and higher education (β=2.18, p<.001) were the final two predictors of the backward variable selection model that explained 39% of the variance (R^2=.39, F(2,79)=25.34, p=<.001) with a statistically significant relationship with resilient coping.

In summary, there were no significant relationships identified between the predictor variables and medication adherence. SBP was a predictor for medication adherence. This relationship suggests BP medication adherence has an impact when BP medications are taken. Although the adherent group in this study demonstrated a lower SBP compared to the non-adherent group, per the new 2017 American College of Cardiology and American Heart Association (ACC/AHA) Blood Pressure guidelines, their SBP was still elevated. The elevated BP readings may indicate non-adherence to other lifestyle factors such as diet and physical activity; however, this study did not examine those factors. Additionally, the participants' baseline SBP prior to initiating therapy and the length of treatment time were not collected. SBP and depressive

symptoms demonstrated a linear relationship with HTN illness perception in the final model, suggesting the presence of depressive symptoms and higher SBP is associated with a more threatening perception of HTN. Likewise, the more threatening HTN is perceived, depressive symptoms increase. This relationship may also demonstrate ineffective coping processes. Depressive symptoms and education were the final two predictors of resilient coping. Higher resilient coping scores were associated with decreased depressive symptoms, while higher education was associated with greater resilient coping scores. Although the sociodemographic variables did not reach inclusion for the final predictor models, belonging to a higher sociodemographic group may yield important health benefits that may eliminate some of the stressors (co-pays, medication affordability, access to provider) associated with illness. In this sample, women who had higher education from 'some college through post-graduate' demonstrated higher resilient coping scores.

Chapter 4

The final manuscript (Chapter 4) addresses both Aim 2 and the exploratory aim of this dissertation study. This manuscript summarizes the findings of the effects that HTN illness perceptions and resilient coping have on BP medication adherence. Additionally, findings from the moderation analysis of resilient coping with high or low stress exposure and HTN medication adherence were explored. The dissertation study hypotheses for Aim 2 were that: (a) greater HTN illness perceptions are associated with increased BP medication adherence, controlling for sociodemographic and clinical factors; (b) greater HTN illness perceptions are associated with both increased resilient coping and BP medication adherence; (c) greater resilient coping is associated with increased BP medication adherence.

Simple logistic regression was performed to examine the relationships of clinical, sociodemographic, and the predictor variables (HTN illness perceptions and resilient coping) with medication adherence. SBP (OR=0.96, p=0.03) was the only covariate with a significant inverse relationship with medication adherence. HTN illness perceptions and resilient coping did not have a significant relationship with medication adherence. However, upon testing each dimension of HTN illness perceptions with adherence, the 'consequence' (OR=0.78, p=0.02) and 'identity' (OR=.76, p=0.02) dimensions were the only dimensions that had a significant relationship with adherence. When stepwise logistic regression with forward variable selection was performed for predictors associated with medication adherence, the remaining predictors in the final model were SBP and the 'consequence' dimension of the HTN illness perception scale (X^2=10.53, p=.001).

The main effects and interaction were tested to determine if resilient coping was a moderator between the relationship of adverse stress exposure and medication adherence. There was no evidence of a statistically significant relationship (z=1.14 p=0.25). Examination of the predictive margins for resilient coping demonstrated that resilient coping scores in the range of 20-38 in conjunction with exposure to adverse stressors (scores 22-30) were significant. When controlling for demographic covariates, the interaction remained non-significant (z=0.05, p=0.59), but those in income categories greater than $96,000 per year did have a statistically significant relationship with adherence. The interaction remained non-significant even when controlling for both clinical covariates and depressive symptoms, while SBP remained significant in both models (without moderation-OR=0.94, p=0.05 with moderation-OR=0.94, p=0.04). There was no statistically significant difference between adherent and non-

adherent participants (OR=1.07, p=0.13) after testing for differences in resilient coping scores with adherence. The interaction term between resilient coping and adverse stress exposure was also not significant (OR=1.01, p=0.23). Further examination of the predictive margins for the relationship between HTN beliefs and resilient coping with medication adherence as the outcome indicates a significant relationship among those who scored lower (7) on the HTN beliefs scale and below the median score (28) for resilient coping. The 'consequence' (OR=0.78, p=0.02) and 'identity' (OR=0.77, p=0.04) dimensions of the HTN illness perception scale demonstrated a significant relationship with resilient coping only in the model without moderation. Examination of the predictive margins demonstrated that resilient coping scores within the range of 20-38, indicating moderate resilient coping, and scores of one (less threatening perception of the associated consequences and symptom experience of HTN) in both dimensions, were significant, but the interaction was not significant.

In summary, the results demonstrate that SBP and the 'consequences' and 'identity' dimensions are associated with medication adherence. The only demographic variable that was associated with adherence in this study was income; specifically, adherence was associated with participants who earned $96,000 per year or more. Careful interpretation of this finding must be appreciated due to the small sample size. HTN illness beliefs or representations and resilient coping, two central constructs of this study, were not associated with medication adherence. Notwithstanding these results, resilient coping did have a statistically significant relationship with education. Compared to only having high school education, persons with some college or higher educational background were associated with greater levels of resilient coping. Likewise, depressive symptoms were inversely associated with resilient coping, suggesting that

resilient coping may serve as a protective buffer against the ills of depression. If resilient coping can buffer against the adverse effects of depression, interventions focusing on increasing resilient coping could potentially impact treatment outcomes. However, larger studies are needed to test this hypothesis.

Discussion

Collectively, these dissertation study findings suggest that adverse social stressors, depressive symptoms, and social support were not associated with HTN beliefs. Additionally, HTN illness perceptions and resilient coping were also not associated with medication adherence; however, the 'consequence' and 'identity' dimensions of the HTN illness beliefs scales were associated with medication adherence. This is suggestive of a few important outcomes. First, illness beliefs can and do vary significantly across populations, gender, and illness condition. Study findings from a lung cancer cohort examining illness beliefs identified the 'concern' dimension for lung cancer as low.[148] This finding contrasts with a preconceived idea that cancer is an illness that would have a higher cause for concern given the morbid connotation associated with this diagnosis. In our study's sample, the 'concern' and 'identity' dimension scores were lower among the adherent group compared to the nonadherent participants. Similar to other studies that examined illness beliefs with treatment outcomes,[147,148] there was no association between cumulative illness beliefs and adherence. Second, nonadherent participants had higher scores for the 'identity' domain compared to the adherent group, suggesting greater symptoms associated with HTN is a strong predictor for poor adherence. Clinically, HTN has been known to be an asymptomatic condition thus making it difficult to operationalize, especially when there are no somatic symptoms prior to or after initiation of medication.[82] This finding demonstrates the

need and importance for clinicians to have open and honest communications regarding HTN in addition to possible medication side effects that may arise in order to better understand any concerns the patient may have regarding diagnosis and treatment. Establishing this type of rapport is necessary in order to promote and increase adherent behavior.

Depression and psychosocial support, two well-established risk factors known for their association with medication nonadherence, were not associated with adherence in this study. Among this study's sample, social support was fairly high and depressive symptom scores were low, indicating the social support network was effective, and depressive symptoms were minimal. Adverse stress exposures were not associated with medication adherence, HTN illness perceptions or resilient coping. Overall, the sample did not show evidence of a substantial amount of exposure to adverse social stressors. Interestingly, adherent persons did report lower scores of adverse stress exposure and depressive symptoms compared to nonadherent participants. Neither of these relationships was statistically significant, but recognizing how these two psychosocial factors can impact health behaviors within a stressful state is important. Discriminatory stressors were associated with decreased adherence in women with lower resilient coping scores. Women who possessed higher resilient coping scores demonstrated better adherence, which indicates resilient coping may serve as a buffer from the adverse effects of discriminatory stressors. Proposals for examining patient level factors, specifically, psychosocial factors, should consider the interaction effects between underlying vulnerabilities.[82] In a study examining adherence in HIV patients with depression, depression alone was not associated with adherence, but depression during stressful periods or stress trigger coping, was associated with nonadherence.[82,152]

SBP and income were the only covariates that were associated with medication adherence. This finding adds to the current body of evidence that demonstrates the association of medication adherence with SBP;[89,145] however, SBP was still nine points higher than the recommended target of 120/80 using the new ACC/AHA blood pressure guidelines.[127] Resilient coping was associated with higher education, and income was associated with HTN illness perceptions. Neither of the sociodemographic covariates remained significant in the final models with medication adherence or HTN illness perceptions, except for resilient coping, where education remained significant in the final model. Socioeconomic status (SES) in general serves as an important indicator for health outcomes.[68] Greater educational attainment or financial status allows for increased access and opportunity overall, and this relationship is not any different in healthcare. Higher SES provides the ability to access information, develop better health literacy, increases access to care, and treatment modalities. Collectively, these things have the ability to impact health outcomes in a tremendous way.

Strengths and Limitations

To the author's knowledge, there are no studies that have examined these constructs collectively utilizing both the CSM and TMSC, specifically among young adult hypertensive AA women. Gaining an understanding of the factors that impact BP medication adherence among a high-risk population adds substantially to the current body of research surrounding this complex behavior. Testing resilient coping as a moderator added to the study's findings, despite the small sample size. Examination of the predictive margins to examine the relationships provided useful information, including higher resilient coping, and may serve as a buffer in how HTN is perceived as an illness. Persons that demonstrated greater resilient coping tended to have a less

threatening perception of HTN compared to those who had a more threatening perception of HTN. Additionally, those who demonstrated lower resilient coping also had lower exposures to adverse stress exposure, indicating exposure to stressors is not always a bad thing as this exposure could potentially help increase the ability to develop resiliency. Overtaxing of this system, however, could prove detrimental to overall cardiovascular health but further testing of this hypothesis is needed.

There are several limitations of this study that must be acknowledged. First, generalizability of the study findings to the overall general population is limited due to the sample of young adult AA women. This limitation may also serve as a strength since these findings have helped to inform greater understanding about a complex health behavior among a relatively high-risk and understudied population. Second, this was a cross-sectional study so causality cannot be established. Despite this limitation, the findings from this study can inform and provide direction for future research questions focused on BP medication adherence. Third, the study sample size was not large enough to detect any interaction effects. Some the relationships did approach statistical significance, however there was not enough power to yield any significant findings. Fourth, approximately 80% of the sample was categorized as non-adherent, limiting the variability of the sample when testing relationships. Additionally, self-reports for each of the concepts under study were ascertained, thus increasing the likelihood for bias for fear of judgment or embarrassment. Finally, the reliability rating of the BIPQ was moderate at .68, so interpretation of the findings from this subscale should be kept in mind.

Implications for the model

Utilizing components of the CSM and TMSC helped to guide and answer the research question in addition to hypotheses testing. Overall, this model was helpful in guiding the study's framework. The CSM helped to elucidate the various dimensions of illness perceptions, thus informing coping processes and their combined effects on medication adherence. The two central constructs of this dissertation study, HTN illness perceptions and resilient coping, did not demonstrate any significant associations with medication adherence; however, dimensions of the HTN illness perception including 'Consequence', and 'Identity' were associated with medication adherence in a bivariate analysis. Further examination of the various dimensions needs further examination. This finding further supports the complex nature surrounding adherence and the various factors that interact to impact this behavior. Regarding illness beliefs, the model did inform the relationship between illness perceptions and coping, demonstrating greater illness perceptions were associated with depression; however, this relationship did not have any effect on adherence in this study. In other studies examining illness perceptions and health outcomes, study findings did not demonstrate any impact on the health outcomes of interest and illness perceptions.[148,153] However, some studies demonstrated a relationship between illness perceptions and emotional representations suggesting that use of this model is helpful when examining both factors together versus taking one dimension of the model for hypothesis testing.

Implications for future research

While this study may not have found significant associations between psychosocial factors, HTN illness representations, and resilient coping with medication adherence, this work does suggest that more research into other aspects of the belief

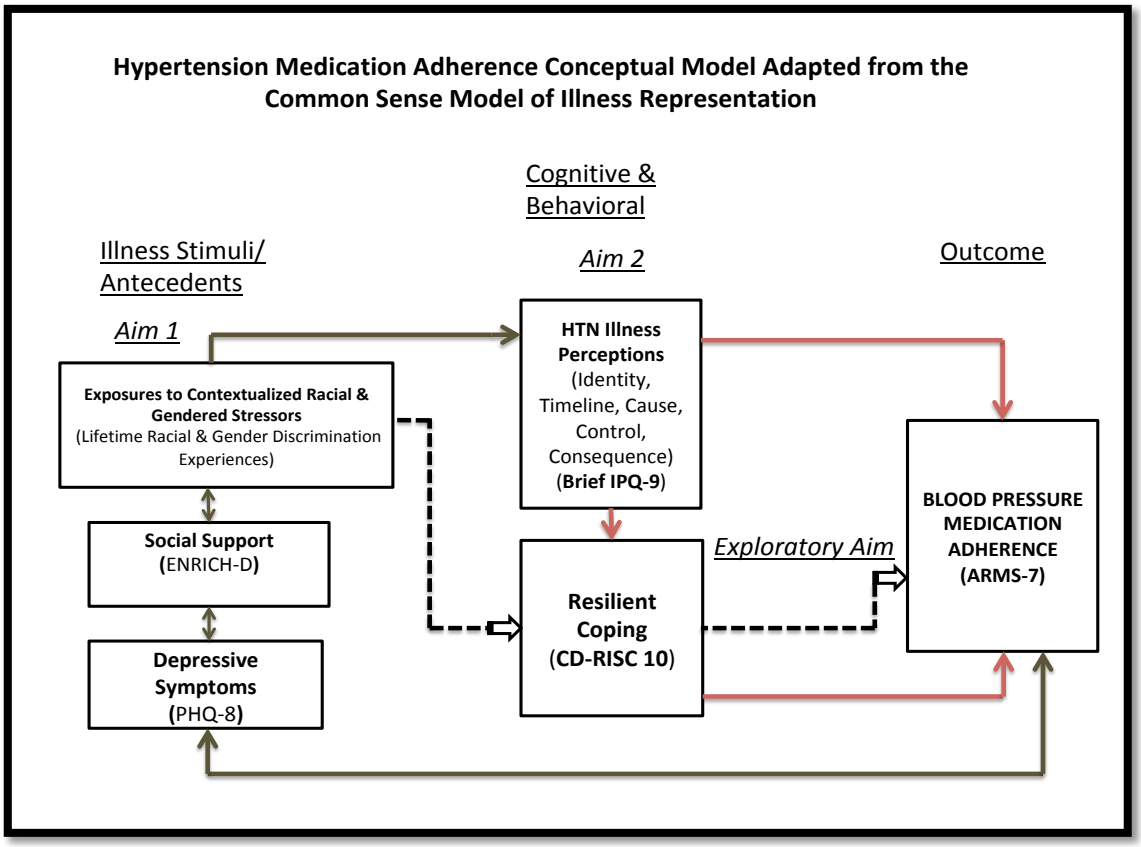
system, lived environment, and psychosocial factors is warranted to investigate in hypertensive AA women. Consideration of complementary theories for hypothesis testing should also be recognized. The CSM seeks to understand factors that facilitate or prohibit health behavior change. In this study, the outcome was not associated with any of the key constructs under study. This is not necessarily a limitation of the model, but other models may be able to better guide hypothesis testing in relation to the outcome under study. Studies have shown that illness beliefs vary and change, indicating the fluidity of this system.[98] Thus, increasing the number of time points for observation of the variables could illuminate these patterns. Gaining a better understanding of the interaction of the lived environment in conjunction with stressors may provide valuable insight into the role of resilience as a buffer to adverse health outcomes. More studies are needed to identify these relationships, ideally in a larger cohort for hypothesis testing. These results have the ability to inform clinical practice. Most importantly, clinicians should recognize the importance of addressing any concerns surrounding HTN and its treatment. For instance, when diagnosing younger patients with HTN that may be from a lower SES, there is an increased risk for medication nonadherence. Additionally, understanding the lack of symptoms associated with HTN also potentiates the risk for nonadherence is important for clinicians to be cognizant. Likewise, those who have a more threatening perception of HTN are also at greater risk for lower adherence. This is why it is also important to assess and question patient's underlying current mental health prior to initiating any type of therapy. If depressive symptoms are present, this could impact coping processes in an adverse way thus increasing the potential for poor adherence. Beliefs are highly complex and eliciting communication

surrounding the illness and treatment modalities has demonstrated to be effective in improving medication adherence and outcomes.[82]

Future Next Steps

Consider a more comprehensive examination of illness perceptions, especially each dimension, in conjunction with blood pressure medication side effects.
Consider illness perceptions, emotional representations, socioeconomic status and baseline psychosocial factors with medication adherence.
Consider exploring the relationship of adherence and resilient coping within the social context of high-risk populations at more than one time point to see if adherence varies or changes.
Consider incorporating blood pressure as an outcome in addition to medication adherence with a larger sample.
Consider assessing three key domains of medication adherence: initiation, maintenance, and sustained phases to determine where adherence varies or changes.

Figure 5.1. Adapted model from the Common Sense Model of Illness Representation



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Appendix A

Permission for Use and Adaptation of Instruments

Adherence to Refills and Measures Scale

Goggins, Kathryn Margaret <kathryn.m.goggins@Vanderbilt.Edu>
Wed 1/4/2017 10:58 AM
Spikes, Telisa;
Kripalani, Sunil <sunil.kripalani@Vanderbilt.Edu>
□
ARMS_Kripalani_ValueHealth 2009.pdf
85 KB
ARMS_7_scoring.docx
15 KB
2 attachments (100 KB)
Download all
Save all to OneDrive - Emory University
Hi Telisa,

Thanks for reaching out to us! I attached a paper describing the ARMS and the scoring guide.

Please let me know if you have any questions or need anything else.

Thanks,
Kathryn

From: Spikes, Telisa [mailto:telisa.spikes@emoryhealthcare.org]
Sent: Tuesday, January 03, 2017 11:30 PM
To: Kripalani, Sunil
Cc: Goggins, Kathryn Margaret
Subject: Re: Permission to use the ARMS-7

Great thank you.

Telisa Spikes, MSN,RN
Emory University Nell Hodgson Woodruff School of Nursing
PhD predoctoral Student
tspikes@emory.edu

From: Kripalani, Sunil <sunil.kripalani@Vanderbilt.Edu>
Sent: Tuesday, January 3, 2017 8:23:30 PM
To: Spikes, Telisa
Cc: Goggins, Kathryn Margaret
Subject: RE: Permission to use the ARMS-7

I'm away from the office but Kathryn can provide

Sunil
On Jan 3, 2017 7:19 PM, "Spikes, Telisa" <telisa.spikes@emoryhealthcare.org> wrote:

Thank you. Where may I get a copy of the instrument with instructions for scoring?

From: Kripalani, Sunil [mailto:sunil.kripalani@Vanderbilt.Edu]
Sent: Tuesday, January 3, 2017 7:20 PM
To: Spikes, Telisa <telisa.spikes@emoryhealthcare.org>
Subject: Re: Permission to use the ARMS-7

Telisa,

Thanks for your interest. You are welcome to use the instrument in your work.

Best,

Sunil

On Jan 3, 2017 3:16 PM, "Spikes, Telisa" <telisa.spikes@emoryhealthcare.org> wrote:

Hi Dr. Kripalani,

I hope this email finds you well. I am a 3rd Year predoctoral student at Emory's Nell Hodgkin School of Nursing under the advisement of Dr. Sandra Dunbar. I would like to request permission to use the ARMS scale for my dissertation project entitled "Hypertensive Medication Adherence In young Aftican American Women". Dr. Stolldorf and I became acquainted at a conference this past fall and she shared this instrument with me.

Please let me know what additional information you may need from me and I will be glad to get this done.

Kind Regards,

Telisa Spikes, MSN,RN
Emory University Nell Hodgson Woodruff School of Nursing
PhD predoctoral Student
tspikes@emory.edu

Brief Illness Perception Questionnaire
Begin forwarded message:

From: Telisa Spikes <telisarn@me.com>

Subject: Fwd: Permission to use the Brief IPQ for dissertation study

Date: September 20, 2018 at 11:02:48 AM EDT

To: Telisa Spikes <tspikes@emory.edu>

Sent from my iPhone

Begin forwarded message:

From: Elizabeth Broadbent <lizbroadbent@me.com>
Date: July 7, 2016 at 5:09:10 PM EDT
To: Telisa Spikes <telisarn@me.com>
Subject: Re: Permission to use the Brief IPQ for dissertation study

Yes

On 8/07/2016, at 7:25 AM, Telisa Spikes <telisarn@me.com> wrote:

Thank you. Do you suggest that I edit the survey to reflect “Hypertension” instead of “illness"?
On Jul 7, 2016, at 3:21 PM, Elizabeth Broadbent <lizbroadbent@me.com> wrote:

Yes you may use it for your study.

On 8/07/2016, at 4:49 AM, Telisa Spikes <telisarn@me.com> wrote:

Good afternoon Dr. Broadbent,

My name is Telisa Spikes and I am a FT doctoral student enrolled in the nursing program at Emory University and I would like to use the Brief IPQ for my dissertation study. My population illness is hypertension. I know that it was stated that the word illness could be substituted with Hypertension. How do I go about revising this seeming the Brief IPQ listed on the website does not provide any detailed instructions?

Thank you in advance,

Telisa Spikes

Connor Davidson Resilience Scale

Jonathan Davidson, M.D. <jonathan.davidson@duke.edu>
Wed 7/6/2016 8:59 AM
Spikes, Telisa

CD-RISC 10 02-20-14.pdf

Dear Telisa:

Thank you for your message. You may use the CD-RISC-10 at no extra cost and a copy is attached.

Best regards,

Jonathan Davidson

From: Spikes, Telisa <telisa.spikes@emoryhealthcare.org>
Sent: Wednesday, July 06, 2016 8:45 AM
To: Jonathan Davidson, M.D.
Subject: CD-RISC 10

Good morning Dr. Davidson,

I purchased the right to use the CD-RISC 25 instrument for my study and as I am getting close to submitting my grant, there are concerns regarding the length of my questionnaires from my committee and I wanted to know if there is an additional cost for me to use the CD-RISC 10 instead of the CD-RISC 25.

Thank you in advance,

Telisa Spikes, MSN,RN, NEA-BC
Emory University Nell Hodgson Woodruff School of Nursing
PhD Student
tspikes@emory.edu

Schedule of Racist and Sexist Events

RE: Permission to use the combined SSE and SRE scale

You replied on Sun 9/23/2018 6:17 PM

Perry, Brea Louise <blperry@indiana.edu>
Tue 2/7/2017 8:27 AM
Spikes, Telisa

Hi Telisa,
Happy to help. Combining the scales was a little tricky because there are some identical items and others that are unique to each scale, and the SRE has different response categories than the SSE. Here are the steps:

1) Recode SRE items so that 4-6=4 (first three categories are identical to SSE)
2) Reverse code any negative items in both scales (you want higher=more gendered racism)
3) For items that are identical in both scales, take the average of SSE and SRE (see below)
4) Take the mean or sum of new combined items and remaining items from each scale (your choice…the former avoids dropping cases with missing data on only a couple of items in the scale)

gen fun=(sse4+sre17r)/2
gen teach=(sse9+sre1r)/2
gen cow=(sse10+sre3r)/2
gen serv=(sse11+sre4r)/2
gen help=(sse13+sre6r)/2
gen job=(sse8+sre2r)/2

egen rs=rowtotal(fun teach cow serv help job sse1 sse6 sse7 sse12 sre5a sre7a sre8a sre9a sre10a sre11a)

Hope this is clear. Let me know if you have questions.
Brea

Brea L. Perry
Associate Professor
Department of Sociology
Indiana University Network Science Institute
Indiana University, Bloomington
http://www.indiana.edu/~soc/bios/Brea_Perry.html

From: Spikes, Telisa [mailto:telisa.spikes@emoryhealthcare.org] **Sent:** Monday, February 6, 2017 3:56 PM **To:** Perry, Brea Louise <blperry@indiana.edu> **Subject:** Permission to use the combined SSE and SRE scale

Hi Dr. Perry,

My name is Telisa Spikes and I am a 3rd year PhD nursing student enrolled in the School of Nursing at Emory University. My dissertation research is focused on Hypertension medication adherence in Young African American women. I am interested in examining how resilience plays a role in facilitating medication adherence in such a high risk group despite exposure to stressors such as racial and gender discrimination. I read your article, "Racial and Gender Discrimination in the Stress Process: Implications for African American Women's Health and Well-Being" and I would very much like to use your combined scale of the SSE and SRE. I did contact Dr. Landrine for permission and she gave me the okay but did state that she was unaware that both scales had been combined so I would need to contact the author that combined both scales for permission to use their specific instrument.

If this is okay, could you provide a copy of the scale in addition to instructions for scoring the instrument?

Kind Regards,

Telisa Spikes, RN, MSN
Emory University Nell Hodgson Woodruff School of Nursing
PhD predoctoral Student
tspikes@emory.edu

Appendix B
Copies of Instruments

Adherence to Refills and Medication Scale-7

Initials:_____ ID# _____ date _____visit site:_____ age _____

Please indicate how much you agree with the following statements as they apply to you over the last ***month****.*

Adherence to Refills and Medicines (ARMS-7)

1. How often do you forget to take your blood pressure medicine?
   1=None of the time 2=Some of the time 3=Most of the time 4=All of the time

2. How often do you decide not to take your blood pressure medicine?
   1=None of the time 2=Some of the time 3=Most of the time 4=All of the time

3. How often do you forget to get your blood pressure prescriptions filled?
   1=None of the time 2=Some of the time 3=Most of the time 4=All of the time

4. How often do you run out of your blood pressure medicine?
   1=None of the time 2=Some of the time 3=Most of the time 4=All of the time

5. How often do you miss taking your blood pressure medicine when you feel better?
   1=None of the time 2=Some of the time 3=Most of the time 4=All of the time

6. How often do you miss taking your blood pressure medicine when you feel sick?
   1=None of the time 2=Some of the time 3=Most of the time 4=All of the time

7. How often do you plan ahead and refill your blood pressure medicines before they run out?
   4=None of the time 3=Some of the time 2=Most of the time 1=All of the time*

Note the scoring on item 7 is flipped

Brief Illness Perception Questionnaire

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your high blood pressure affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your high blood pressure will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your high blood pressure?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your high blood pressure?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your high blood pressure?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your high blood pressure?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your high blood pressure?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

How much does your high blood pressure affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
not at all affected										extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your high blood pressure. *The most important causes for me:*

1. _____

2. _____

3. _____

CD-RISC 10

Connor-Davidson Resilience Scale 10 (CD-RISC-10) ©

initials ☐☐☐ *ID#* ☐☐☐☐☐☐☐ *date* ☐☐/☐☐/☐☐☐☐ *visit* ☐☐ *age* ☐☐

*Please indicate how much you agree with the following statements as they apply to you over the last **month**. If a particular situation has not occurred recently, answer according to how you think you would have felt.*

		not true at all (0)	rarely true (1)	sometimes true (2)	often true (3)	true nearly all the time (4)
1.	I am able to adapt when changes occur.	☐	☐	☐	☐	☐
2.	I can deal with whatever comes my way.	☐	☐	☐	☐	☐
3.	I try to see the humorous side of things when I am faced with problems.	☐	☐	☐	☐	☐
4.	Having to cope with stress can make me stronger.	☐	☐	☐	☐	☐
5.	I tend to bounce back after illness, injury, or other hardships.	☐	☐	☐	☐	☐
6.	I believe I can achieve my goals, even if there are obstacles.	☐	☐	☐	☐	☐
7.	Under pressure, I stay focused and think clearly.	☐	☐	☐	☐	☐
8.	I am not easily discouraged by failure.	☐	☐	☐	☐	☐
9.	I think of myself as a strong person when dealing with life's challenges and difficulties.	☐	☐	☐	☐	☐
10.	I am able to handle unpleasant or painful feelings like sadness, fear, and anger.	☐	☐	☐	☐	☐

02-20-14

Enhancing Social Support Inventory

Initials:_____ ID# _____ date _____visit site:_____ age _____

ENRICHED SOCIAL SUPPORT INSTRUMENT (ESSI)

Please read the following questions and circle the response that most closely describes your current situation.

1. Is there someone available to you whom you can count on to listen to you when you need to talk?

None of the time	A little of the time	Some of the time	Most of the time	All the time
1	2	3	4	5

2. Is there someone available to give you good advice about a problem?

None of the time	A little of the time	Some of the time	Most of the time	All the time
1	2	3	4	5

3. Is there someone available to you who shows you love and affection?

None of the time	A little of the time	Some of the time	Most of the time	All the time
1	2	3	4	5

4. Is there someone available to help you with daily chores?

None of the time	A little of the time	Some of the time	Most of the time	All the time
1	2	3	4	5

5. Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?

None of the time	A little of the time	Some of the time	Most of the time	All the time
1	2	3	4	5

6. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?

None of the time	A little of the time	Some of the time	Most of the time	All the time
1	2	3	4	5

7. Are you currently married or living with a partner?

Yes No

Depressive Symptoms

Personal Health Questionnaire Depression Scale (PHQ-8)

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?
*(circle **one** number on each line)*

How often during the past 2 weeks were you bothered by...	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

Scoring

If two consecutive numbers are circled, score the higher (more distress) number. If the numbers are not consecutive, do not score the item. Score is the sum of the 8 items. If more than 1 item missing, set the value of the scale to missing. A score of 10 or greater is considered major depression, 20 or more is severe major depression.

Characteristics

Tested on 1165 subjects with chronic conditions.

No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
8	0-24	6.63	5.52	.86	NA

Source of Psychometric Data

U.S. National Chronic Disease Self-Management Study. Study described in Ory MG, Ahn S, Jiang L, et al. National study of chronic disease self-management: six month outcome findings. Journal of Aging and Health. 2013 [in press].

Comments

This is an adaptation of the PHQ-9 scale. Since this scale is self-administered in our studies, question #9, "How often during the past 2 weeks were you bothered by thoughts that you would be better off dead, or of hurting yourself in some way?", was deleted. This scale available in Spanish.

References

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Razykov I, Ziegelstein RC, Whooley MA, Thombs BD. The PHQ-9 versus the PHQ-8--is item 9 useful for assessing suicide risk in coronary artery disease patients? Data from the Heart and Soul Study. J Psychosom Res. 2012; 73(3):163-168.

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Funded by the National Institute of Nursing Research (NINR)

Schedule of Racist and Sexist Events

Initials:_____ ID# _____ date _____visit site:_____ age _____

The Schedule of Racist Events (SRE) is a self-report inventory measuring frequency with which African Americans have experienced specific racist events (types of discrimination). Items 1-17 are answered twice; once for the frequency of the racist event during one's entire lifetime, and once for the appraisal of the stressfulness of the racist events.

How many times in your lifetime?

Response Categories are as follow:
1-this has never happened
2-this has happened Once in a While (less than 10% of the time)
3-this has happened SOMETIMES (10%-25% of the time)
4-this has happened A LOT (26%-49% of the time),
5-this has happened MOST OF THE TIME (50%-70% of the time)
6-this has happened ALMOST ALL OF THE TIME (more than 70% of the time)

1. How many times have you been treated unfairly by teachers and professors because you are Black?
   1 2 3 4 5 6
2. How many times have you have been treated unfairly by your employers, bosses and supervisors because you are Black?
   1 2 3 4 5 6
3. How many times have you been treated unfairly by your co-workers, fellow students and colleagues because you are Black?
   1 2 3 4 5 6
4. How many times have you been treated unfairly by people in service jobs (store clerks, waiters, bartenders, bank tellers, and others) because you are Black?
   1 2 3 4 5 6
5. How many times have you been treated unfairly by strangers because you are Black?
   1 2 3 4 5 6
6. How many times have you been treated unfairly by people in helping jobs (doctors, nurses, psychiatrists, case workers, dentists, school counselors, therapists, social workers, and others) because you are Black?
   1 2 3 4 5 6
7. How many times have you been treated unfairly by neighbors because you are Black?
   1 2 3 4 5 6

Initials:_____ ID# _____ date _____visit site:_____ age _____

8. How many times have you been treated unfairly by institutions (schools, universities, law firms, the police, the courts, the Department of Social Services, the Unemployment Office and others) because you are Black?

   1 2 3 4 5 6

9. How many times have you been treated unfairly by people that you thought were your friends because you are Black?

   1 2 3 4 5 6

10. How many times have you been accused or suspected of doing something wrong (such as stealing, cheating, not doing your share of the work, or breaking the law) because you are Black?

    1 2 3 4 5 6

11. How many times have people misunderstood your intentions and motives because you are Black?

    1 2 3 4 5 6

12. How many times did you want to tell someone off for being racist but didn't say anything?

    1 2 3 4 5 6

13. How many times have you been really angry about something racist that was done to you?

    1 2 3 4 5 6

14. How many times were you forced to take drastic steps (such as filing a grievance, filing a lawsuit, quitting your job, moving away, and other actions) to deal with some racist thing that was done to you?

    1 2 3 4 5 6

15. How many times have you been called a racist name like nigger, coon, jungle bunny or other names?

    1 2 3 4 5 6

16. How many times have you gotten into an argument or a fight about something racist that was done you or done to somebody else?

    1 2 3 4 5 6

17. How many times have you been made fun of, picked on, pushed, shoved, hit, or threatened with harm because you are Black?

    1 2 3 4 5 6

<u>For item #18 ONLY:</u>

Initials:_____ ID# _____ date _____visit site:_____ age _____

18. How different would your life be now if you HAD NOT BEEN treated in a racial and unfair way?
    a. Same as now
    b. A little different
    c. Different in a few ways
    d. Different in a lot of ways
    e. Different in most ways
    f. Totally different

Part 2 of SRE Questionnaire- **How stressful was this for you?**

Response Categories are as follow:
1 Not at all
2
3
4
5
6 Extremely

---

1. How many times have you been treated unfairly by teachers and professors because you are Black?

   1 2 3 4 5 6

2. How many times have you have been treated unfairly by your employers, bosses and supervisors because you are Black?

   1 2 3 4 5 6

3. How many times have you been treated unfairly by your co-workers, fellow students and colleagues because you are Black?

   1 2 3 4 5 6

4. How many times have you been treated unfairly by people in service jobs (store clerks, waiters, bartenders, bank tellers, and others) because you are Black?

   1 2 3 4 5 6

5. How many times have you been treated unfairly by strangers because you are Black?

   1 2 3 4 5 6

6. How many times have you been treated unfairly by people in helping jobs (doctors, nurses, psychiatrists, case workers, dentists, school counselors, therapists, social workers, and others) because you are Black?

   1 2 3 4 5 6

7. How many times have you been treated unfairly by neighbors because you are Black?

   1 2 3 4 5 6

Initials:_____ ID# _____ date _____visit site:_____ age _____

8. How many times have you been treated unfairly by institutions (schools, universities, law firms, the police, the courts, the Department of Social Services, the Unemployment Office and others) because you are Black?

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1 2 3 4 5 6

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13. How many times have you been really angry about something racist that was done to you?

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14. How many times were you forced to take drastic steps (such as filing a grievance, filing a lawsuit, quitting your job, moving away, and other actions) to deal with some racist thing that was done to you?

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1 2 3 4 5 6

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1 2 3 4 5 6

Initials:_____ ID#_____ date_____ visit site:_____ age:_____

Schedule of Sexist Events-Lifetime (SSE-LM)

"As a woman, how often…"

1. Have people made inappropriate or unwanted sexual advances at you?
   Never Rarely Sometime Often

2. Have you been really angry about something sexist that was done to you? (By "sexist" we mean when you receive unfair treatment because you are a woman)
   Never Rarely Sometime Often

3. Have you been called a sexist name like bitch, cunt, chick, or other names?
   Never Rarely Sometime Often

4. Have you been made fun, picked on, pushed, shoved, hit or threatened with harm?
   Never Rarely Sometime Often

5. Have you been really angry about sexist or sexual jokes?
   Never Rarely Sometime Often

6. Have you been treated unfairly by your boyfriend, husband, or other important men in your life?
   Never Rarely Sometime Often

7. Have you been treated unfairly by your family?
   Never Rarely Sometime Often

8. Have you been treated unfairly by your employers, bosses, and supervisors?
   Never Rarely Sometime Often

9. Have you been treated unfairly by teachers, school administrators and coaches?
   Never Rarely Sometime Often

10. Have you been treated unfairly by your co-workers or fellow students?
    Never Rarely Sometime Often

11. Have you been treated unfairly by people in service jobs such as store clerks or waiters?

    Never Rarely Sometime Often

12. Have you been denied a raise, promotion, a job or something at work you deserved?
    Never Rarely Sometime Often

13. Have you been treated unfairly by people in helping jobs such as doctors, nurses, or dentists?
    Never Rarely Sometime Often

Appendix C

Copies of Institutional Review Board Approvals

EMORY UNIVERSITY | Institutional Review Board

TO: Sandra Dunbar
Principal Investigator
Surg Serv Admin

DATE: February 12, 2018

RE: **Expedited Approval**
IRB00100504
Hypertensive Medication Adherence in Young African American Women

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory categories F(2b), F(4), F(7) as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on **February 8, 2018** and granted approval effective from **February 8, 2018** through **February 7, 2019**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Study Protocol v. 1/12/2018
- Recruitment:
  - Dissertation flier
- Questionnaires:
  - Depressive symptoms
  - Illness Beliefs
  - Medication Adherence
  - Resilient coping
  - Schedule of Racist events
  - Schedule of sexist events
  - Social Support ESSI
- Study Consent v. 11/26/2017
- A partial HIPAA waiver has been approved/renewed by the Emory University IRB for the purpose of identifying potential subjects for this protocol. This waiver was reviewed and approved under the review procedure as noted above. The approval is granted based on the IRB's determination that all criteria for the waiver of authorization have been met. As subjects are contacted, you are required to obtain authorization.

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

questions. Terms and conditions of sponsors, if any, also apply to reporting.

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

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

Maria-Gracia Beltran
Research Protocol Analyst
This letter has been digitally signed

CC:

Higgins	Melinda	*SON: Nursing Research
Lewis	Tene	*SPH: Epidemiology
Spikes	Telisa	Surg Serv Admin

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu/
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EMORY UNIVERSITY | Institutional Review Board

TO: Telisa Spikes, MSN RN NEA-BC
Principal Investigator
GRS: Nursing

DATE: May 23, 2017

RE: **Expedited Approval**
IRB00095352
Hypertensive Medication Adherence In Young African American Women

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory category F7 as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 5/21/2017 and granted approval effective from **5/21/2017** through **5/20/2018**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above.

A partial waiver of HIPAA authorization has been approved by the IRB for the purpose of identifying potential subjects for this protocol. As subjects are contacted, you are required to obtain their HIPAA authorization.

The following documents are acknowledged or otherwise approved for use:

- Study Protocol, version date
- Consent and HIPAA authorization form, version date 5/21/2017
- Research Instruments:
  - ARMS-7
  - BIPQ
  - CD-RISQ 10
  - ESSI
  - SSE & SRE
  - 10,000 Women Demographic Form

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

Before implementing any change to this protocol (including but not limited to sample size,

informed consent, study design, you must submit an amendment request and secure IRB approval.

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

Samuel Roberts
Senior Research Protocol Analyst
This letter has been digitally signed

CC:	Dunbar	Sandra	Surg Serv Admin
	Higgins	Melinda	*SON: Nursing Research
	Lewis	Tene	*SPH: Epidemiology
	Lundberg	Gina	SOM: Medicine: Cardiology

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EMORY UNIVERSITY | Institutional Review Board

TO: Sandra Dunbar
Principal Investigator
*SON: Academic Advancement

DATE: August 17, 2018

RE: **Notification of Amendment Approval**
AM2_IRB00100504
IRB00100504
Hypertensive Medication Adherence in Young African American Women

Thank you for submitting an amendment request. The Emory IRB reviewed and approved this amendment under the expedited review process on **August 15, 2018**. This amendment includes the following:

Changes to Consent Form(s):

- Revised consent

Changes to Protocol Forms:

- Revised Study protocol

Changes to study sites:

- Added: Grady Health System (CRN)

Important note: If this study is NIH-supported, you may need to obtain NIH prior approval for the change(s) contained in this amendment before implementation. Please review the NIH policy directives found at the following links and contact your NIH Program Officer, NIH Grants Management Officer, or the Emory Office of Sponsored Programs if you have questions.

Policy on changes in active awards: http://grants.nih.gov/grants/guide/notice-files/NOT-OD-12-129.html

Policy on delayed onset awards: http://grants.nih.gov/grants/guide/notice-files/NOT-OD-12-130.html

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

Sincerely,

Maria-Gracia Beltran, BA
Research Protocol Analyst
This letter has been digitally signed

CC

Higgins	Melinda	*SON: Nursing Research
Lewis	Tene	*SPH: Epidemiology
Spikes	Telisa	GRS: Nursing

Emory University IRB
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu/
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Appendix D
Consent Forms

You Are Being Asked to Be in a Research Study

What Is a Research Study?
The main purpose of research studies is to gain knowledge. This knowledge may be used to help others. Research studies are not intended to benefit you directly, though some might.

Do I Have to Do This?
No. Being in this study is entirely your choice. If you decide to join this study, you can change your mind later on and withdraw from the research study.

Taking part in a study is separate from medical care. The decision to join or not join the research study will not affect your status as a patient.

What Is This Document?
This form is an informed consent document. It will describe the study risks, procedures, and any costs to you.

This form is also a HIPAA Authorization document. It will describe how your health information will be used and by whom.

Signing this form indicates you are willing to take part in the study and allow your health information to be used.

What Should I Do Next?
1. Read this form, or have it read to you.
2. Make sure the study doctor or study staff explains the study to you.
3. Ask questions (e.g., time commitment, unfamiliar words, specific procedures, etc.)
4. If there will be medical treatment, know which parts are research and which are standard care.
5. Take time to consider this, and talk about it with your family and friends.

Emory University
Consent to be a Research Subject / HIPAA Authorization

Title: Hypertensive Medication Adherence In Young African American Women

Principal Investigator: Telisa Spikes, MSN, RN, Nell Hodgson School of Nursing

Sponsor: Dr. Sandra Dunbar

Investigator-Sponsor: N/A

Study-Supporter: National Institute of Nursing Research and Emory University Professional Development Funds

Introduction
You are being asked to be in a medical research study. This form is designed to tell you everything you need to think about before you decide if you want to be a part of the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.** The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

Before making your decision:
- Please carefully read this form or have it read to you
- Please listen to the study doctor or study staff explain the study to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. You may wish to discuss your decision with family or friends. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you. By signing this form you will not give up any legal rights.

What is the purpose of this study?
The purpose of this study is to examine factors and variations that enhance blood pressure medication adherence among a sample of 110 African American women 18-45 years of age.

What will I be asked to do?
You will be asked to participate in a research study that will take approximately 1-hour to complete. You will be asked to: complete an intake form providing personal information about you and your health history, seven questionnaires related to the research study, provide a small blood sample to measure your cholesterol level, and lastly, recording of 2-resting blood pressure readings.

Who owns my study information and samples?
If you join this study, you will be donating your samples and study information. You will not receive any compensation if your samples or information are used to make a new product. Since this study only requires one meeting, the likelihood for you to withdraw is minimal; however, if you decide to

withdraw from the study prior to obtaining any information or decline request of the study to use your information once it has been collected, all data will be destroyed and samples will be discarded.

What are the possible risks and discomforts?

All reasonably foreseeable risks and discomforts associated with your participation in the study include disclosure of confidential information, possible emotional distress in completing questionnaires, and discovery of high blood pressure levels.

There may be side effects from the study procedure or procedures that are not known at this time.

- Scores from both the depressive symptoms and stressful life events questionnaires will be reviewed immediately post-completion.
- If it is revealed that you are experiencing significant depressive symptoms, you will be contacted and counseled about the finding and asked to contact your healthcare provider. In the event that you do not have a primary healthcare provider, a reference of Emory Healthcare providers can be given to you upon your request.
- If acceptable, the data will be shared with your provider, and you may be referred to the Emory Healthcare Resident Psychiatry Services for further evaluation or treatment for depressive symptoms.
- There are no additional funds to cover this service.
- In the Emory Healthcare System and greater Atlanta community, there are several mental health services available to you for a fee.
- The depressive symptoms questionnaire does not confer a diagnosis of clinical depression.

The most common risks and discomforts expected in this study are:

- 50% probability of having a sore finger due to a needle stick to collect a blood sample to obtain your cholesterol level
- 10% probability of a sore arm due to the temporary inflation of the blood pressure cuff, which should be alleviated once the blood pressure cuff has been released.

Rare but possible risks include: minor bruising of the finger from receiving a needle stick and infection due to blood draw. All precautions will be taken to ensure the likelihood of an infection is decreased and minimized by performing proper hand washing before and after the collection of your blood sample.

It is possible that the researchers will learn something new during the study about the risks of being in it. If this happens, they will tell you about it. Then you can decide if you want to continue to be in this study or not. You may be asked to sign a new consent form that includes the new information if you decide to stay in the study.

Will I benefit directly from the study?

This study is not designed to benefit you directly. This study is designed to learn more about factors that enhance hypertension medication adherence in African American women whom are predisposed to worse outcomes due to uncontrolled high blood pressure. The study results may be used to help others in the future by developing interventions that can increase medication adherence.

Will I be compensated for my time and effort?

You will receive $25^{00} for completion of the study visit to compensate you for your time and effort. You can decline payment if you are concerned about confidentiality, or you can talk to the study team to see if there are other payment options.

What are my other options?

If you decide not to enter this study, all study discussion will be terminated.

How will you protect my private information that you collect in this study?

Whenever possible, a study number, rather than your name, will be used on study records. Your name and other identifying information will not appear when we present or publish the study results.

Storing and Sharing your Information

De-identified data from this study, including your de-identified genetic information, may be shared with the research community at large to advance science and health. Data from this study may be placed into public databases where, in addition to having no direct identifiers, researchers will need to sign data use agreements before accessing the data. We will remove or code any personal information that could identify you before your information is shared. This will ensure that, by current scientific standards and known methods, it is extremely unlikely that anyone would be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.

Medical Record

If you have been an Emory Healthcare patient before, then you already have an Emory Healthcare medical record. If you have never been an Emory Healthcare patient, you do not have one.

The results of some study tests and procedures will be used only for research purposes and will *not* be placed in your medical record. For this study, those items include: **Atherosclerotic cardiovascular disease score (ASCVD)**, a metric that estimates 10-year and lifetime risk for coronary death or nonfatal myocardial infarction or fatal or nonfatal stroke calculated from age, sex, race, total cholesterol, HDL cholesterol, systolic blood pressure, blood pressure lowering medication use, diabetes status, and smoking status; **Body Mass Index (BMI),** a measure of body fat based on your reported weight and height, **Cholesterol level** and **Blood pressure**.

Tests and procedures done at non-Emory places may not become part of your Emory medical record. Also, if you decide to be in this study, it is up to you to let your other health providers know.

Costs

There are no costs, research or standard of care related, associated with the study.

There will be no costs to you for participating in this study, other than basic expenses like transportation. You will not be charged for any of the research activities. If the study procedures result in any medical complications that would not fall under “injury” as discussed above, the cost of treatment for those complications may be charged to you or your insurance.

Withdrawal from the Study

You have the right to leave a study at any time without penalty.

The researchers also have the right to stop your participation in this study without your consent for any reason, especially if they believe it is in your best interest or if you were to object to any future changes that may be made in the study plan.

Authorization to Use and Disclose Protected Health Information

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act and regulations (HIPAA). We refer to all of these laws as the "Privacy Rules." Here we let you know how we will use and disclose your PHI for the single study.

PHI that Will be Used/Disclosed:

The PHI that we will use or share for the main research study includes:

- Date and year of birth
- Medical history and Comorbidities.
- Clinical measurement (BMI & Cholesterol).
- Current Medications
- Blood Pressure reading

Purposes for Which Your PHI Will be Used/Disclosed:

We will use and share your PHI for the conduct and oversight of the research study. We will use and share your PHI to provide you with study related treatment. We will also use and share your PHI to conduct normal business operations. We may share your PHI with other people and places that help us conduct or carry out the study, such as laboratories, data management centers, data monitors, contract research organizations, Institutional Review Boards (IRBs) and other study sites. If you leave the study, we may use your PHI to determine your health, vital status or contact information.

Use and Disclosure of Your Information That is Required by Law:

We will use and disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults. We will also comply

with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Authorization to Use PHI is Required to Participate:
By signing this form, you give us permission to use and share your PHI as described in this document. You do not have to sign this form to authorize the use and disclosure of your PHI. If you do not sign this form, then you may not participate in the research study or receive research-related treatment. You may still receive non-research related treatment.

People Who will Use/Disclose Your PHI:
The following people and groups will use and disclose your PHI in connection with the research study:

- The Principal Investigator, Telisa Spikes, and the research staff will use and disclose your PHI to conduct the study.
- Emory may use and disclose your PHI to run normal business operations.
- The Principal Investigator and research staff will share your PHI with other people and groups to help conduct the study or to provide oversight for the study.
- Dr. Sandra Dunbar is the Sponsor of the study. The Sponsor may use and disclose your PHI to make sure the research is done correctly and to collect and analyze the results of the research. The Sponsor may disclose your PHI to other people and groups like study monitors to help conduct the study or to provide oversight for the study.
- The research team may use and disclose your PHI, including disclosure to insurance carriers to administer payment for subject injury.
- The following people and groups will use your PHI to make sure the research is done correctly and safely:
    - Emory offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research.
    - Government agencies that regulate the research including: Office for Human Research Protections.
    - Public health agencies.
    - Research monitors and reviewer.
    - Accreditation agencies.
    - Office of Nursing Research
    - Dr. Gina Lundberg
- Sometimes a Principal Investigator or other researcher moves to a different institution. If this happens, your PHI may be shared with that new institution and their oversight offices. PHI will be shared securely and under a legal agreement to ensure it continues to be used under the terms of this consent and HIPAA authorization.

Expiration of Your Authorization
Your PHI will be used until this research study ends.

Revoking Your Authorization
If you sign this form, at any time later you may revoke (take back) your permission to use your information. If you want to do this, you must contact the study team at: 404-493-1161

At that point, the researchers would not collect any more of your PHI. But they may use or disclose the information you already gave them so they can follow the law, protect your safety, or make sure that the study was done properly and the data is correct. If you revoke your authorization you will not be able to stay in the study.

Other Items You Should Know about Your Privacy
Not all people and entities are covered by the Privacy Rules. HIPAA only applies to health care providers, health care payers, and health care clearinghouses. If we disclose your information to people who are not covered by the Privacy Rules, including HIPAA, then your information will not be protected by the Privacy Rules. People who do not have to follow the Privacy rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them.

To maintain the integrity of this research study, you generally will not have access to your PHI related to this research until the study is complete. When the study ends, and at your request, you generally will have access to your PHI that we maintain in a designated record set. A designated record set is data that includes medical information or billing records that your health care providers use to make decisions about you. If it is necessary for your health care, your health information will be provided to your doctor.

We may remove identifying information from your PHI. Once we do this, the remaining information will not be subject to the Privacy Rules. Information without identifiers may be used or disclosed with other people or organizations for purposes besides this study.

Voluntary Participation and Withdrawal from the Study
You have the right to leave a study at any time without penalty. You may refuse to do any procedures you do not feel comfortable with, or answer any questions that you do not wish to answer. In the event that you decide to withdraw from this study, you may not request for your information to be used.

Contact Information
Contact [Telisa Spikes, MSN, RN] at [404-493-1161]

- if you have any questions about this study or your part in it,
- if you feel you have had a research-related injury, or
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

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

Consent and Authorization

TO BE FILLED OUT BY SUBJECT ONLY

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

_____
Name of Subject

_____ _____
Signature of Subject (18 or older and able to consent) **Date** **Time**

TO BE FILLED OUT BY STUDY TEAM ONLY

_____
Name of Person Conducting Informed Consent Discussion

_____ _____
Signature of Person Conducting Informed Consent Discussion **Date** **Time**

Study No.: IRB00095352 **Emory University IRB** IRB use only Document Approved On: 5/21/2017

Emory University
Consent to be a Research Subject and
HIPAA Authorization Form

Title: Hypertensive Medication Adherence in Young African American Women

Principal Investigator: Telisa Spikes MSN, RN, NEA-BC Nell Hodgson Woodruff School of Nursing Emory University & Dr. Gina Lundberg, MD, Emory Women's Heart Center

Introduction

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

Before making your decision:

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

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

Study Overview

The purpose of this study is to understand unique stressors and psychosocial challenges faced by younger hypertensive AA women and how these challenges affect health outcomes and self-management behavior, specifically medication adherence, in achieving blood pressure control. The study seeks to enroll 110 African American women aged 18-45 years of age.

Procedures

This study only involves one visit with the researcher. Prior to obtaining any study information, study details will be given to you so that you will be able to make an informed decision of your participation into the study that will be followed by obtainment of informed consent. During the study visit, you will be asked about your health history based upon the information you provided on the clinical demographic form of the "10,000 Women" parent study. We will also analyze data collected from you as part of the "10,000 Women" study. Once your health history has been verified, you will be asked to complete 5 questionnaires specific to the study. The total duration of this visit is expected to be 45 minutes or less. At the completion of the questionnaires and prior to conclusion of the study visit, we will review all questionnaires for completion and verify that any missed responses were missed because you wanted to skip those questions.

Risks and Discomforts

All reasonably foreseeable risks and discomforts associated with your participation in the study include disclosure of confidential information, possible emotional distress in completing questionnaires, and discovery of high blood pressure levels.

- Scores from both the depressive symptoms and stressful life events questionnaires will be reviewed immediately post-completion.

- If it is revealed that you are experiencing significant depressive symptoms, you will be contacted and counseled about the finding and asked to contact your healthcare provider. In the event that you do not have a primary healthcare provider, a reference of Emory Healthcare providers can be given to you upon your request.
- If acceptable, the data will be shared with your provider, and you may be referred to the Emory Healthcare Resident Psychiatry Services for further evaluation or treatment for depressive symptoms.
- There are no additional funds to cover this service.
- In the Emory Healthcare System and greater Atlanta community, there are several mental health services available to you for a fee.
- The depressive symptom questionnaire does not confer a diagnosis of clinical depression.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about factors that enhance hypertension medication adherence in African American women whom are predisposed to worse outcomes due to uncontrolled high blood pressure. The study results may be used to help others in the future by developing interventions that can increase medication adherence.

Compensation

You will receive $_25^{00}_ for completion of the study visit. You can decline payment if you are concerned about confidentiality, or you can talk to the study team to see if there are other payment options.

Confidentiality

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

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

Authorization to Use and Disclose Protected Health Information

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act and regulations (HIPAA). We refer to all of these laws as the "Privacy Rules." Here we let you know how we will use and disclose your PHI for the single study.

PHI that Will be Used/Disclosed:

The PHI that we will use or share for the main research study includes:

- Date and year of Birth
- Medical history and Comorbidities
- Clinical measurement (BMI, Cholesterol, Glucose)
- Current medications
- Blood Pressure reading

Purposes for Which Your PHI Will be Used/Disclosed:

We will use and share your PHI for the conduct and oversight of the research study. We will use and share your PHI to provide you with study related treatment. Compensation in the form of a $25 gift card will be provided to the participant for completion of the study questionnaires. We will also use and share your PHI to conduct normal business operations. We may share your PHI with other people and places that help us conduct or carry out the study, such as laboratories, data management centers, data monitors, contract research organizations, Institutional Review Boards (IRBs) and other study sites. If you leave the study, we may use your PHI to determine your health, vital status or contact information.

Use and Disclosure of Your Information That is Required by Law:
We will use and disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults. We will also comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Authorization to Use PHI is Required to Participate:
By signing this form, you give us permission to use and share your PHI as described in this document. You do not have to sign this form to authorize the use and disclosure of your PHI. If you do not sign this form, then you may not participate in the research study or receive research-related treatment. You may still receive non-research related treatment.

People Who will Use/Disclose Your PHI:
The following people and groups will use and disclose your PHI in connection with the research study:

- The Principal Investigators and the research staff will use and disclose your PHI to conduct the study and give you study related treatment.
- Emory may use and disclose your PHI to get payment for study related treatment and to run normal business operations.
- The Principal Investigators and research staff will share your PHI with other people and groups to help conduct the study or to provide oversight for the study.
- Dr. Sandra Dunbar is the Sponsor of the study. The Sponsor may use and disclose your PHI to make sure the research is done correctly and to collect and analyze the results of the research. The Sponsor may disclose your PHI to other people and groups like study monitors to help conduct the study or to provide oversight for the study.
- The following people and groups will use your PHI to make sure the research is done correctly and safely:
    - Emory offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research.
    - Public health agencies.
    - Research monitors and reviewer.
    - Accreditation agencies.
    - Office of Nursing Research.
    - Dr. Gina Lundberg

Expiration of Your Authorization
Your PHI will be used until this research study ends.

Revoking Your Authorization
If you sign this form, at any time later you may revoke (take back) your permission to use your information. If you want to do this, you must contact the study team at 404-493-1161.

At that point, the researchers would not collect any more of your PHI. But they may use or disclose the information you already gave them so they can follow the law, protect your safety, or make sure that the study was done properly and the data is correct. If you revoke your authorization you will not be able to stay in the study.

Other Items You Should Know about Your Privacy
Not all people and entities are covered by the Privacy Rules. HIPAA only applies to health care providers, health care payers, and health care clearinghouses. If we disclose your information to people who are not covered by the Privacy Rules, including HIPAA, then your information won't be protected by the Privacy Rules. People who do not have to follow the Privacy rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them.

To maintain the integrity of this research study, you generally will not have access to your PHI related to this research until the study is complete. When the study ends, and at your request, you generally will have access to your PHI that we maintain in a designated record set. A designated record set is data that includes medical information or billing records that your health care providers use to make decisions about you. If it is necessary for your health care, your health information will be provided to your doctor.

We may remove identifying information from your PHI. Once we do this, the remaining information will not be subject to the Privacy Rules. Information without identifiers may be used or disclosed with other people or organizations for purposes besides this study.

Voluntary Participation and Withdrawal from the Study
You have the right to leave a study at any time without penalty. You may refuse to do any procedures you do not feel comfortable with, or answer any questions that you do not wish to answer. In the event that you decide to withdraw form this study, you may not request for your information to be used.

Contact Information
Contact [Telisa Spikes, MSN RN, NEA-BC] at [404-493-1161]:

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

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

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

Consent

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

_____
Name of Subject

_____ _____
Signature of Subject Date Time

_____ _____
Signature of Person Conducting Informed Consent Discussion Date Time

You Are Being Asked to Be in a Research Study

What Is a Research Study?

The main purpose of research studies is to gain knowledge. This knowledge may be used to help others. Research studies are not intended to benefit you directly, though some might.

Do I Have to Do This?

No. Being in this study is entirely your choice. If you decide to join this study, you can change your mind later on and withdraw from the research study.

Taking part in a study is separate from medical care. The decision to join or not join the research study will not affect your status as a patient.

What Is This Document?

This form is an informed consent document. It will describe the study risks, procedures, and any costs to you.

This form is also a HIPAA Authorization document. It will describe how your health information will be used and by whom.

Signing this form indicates you are willing to take part in the study and allow your health information to be used.

What Should I Do Next?

1. Read this form, or have it read to you.
2. Make sure the study doctor or study staff explains the study to you.
3. Ask questions (e.g., time commitment, unfamiliar words, specific procedures, etc.)
4. If there will be medical treatment, know which parts are research and which are standard care.
5. Take time to consider this, and talk about it with your family and friends.

Emory University and Grady Health System
Consent to be a Research Subject / HIPAA Authorization

Title: Hypertensive Medication Adherence in Young African American Women

Principal Investigator: Telisa Spikes, MSN, RN, Nell Hodgson Woodruff School of Nursing

Sponsor: Dr. Sandra Dunbar

Investigator-Sponsor: N/A

Study-Supporter: National Institute of Nursing Research and Emory University Professional Development Funds

Introduction
You are being asked to be in a medical research study. This form is designed to tell you everything you need to think about before you decide if you want to be a part of the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.** The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

Before making your decision:
- Please carefully read this form or have it read to you
- Please listen to the study doctor or study staff explain the study to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. You may wish to discuss your decision with family or friends. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you. By signing this form you will not give up any legal rights.

What is the purpose of this study?
The purpose of this study is to examine factors and variations that enhance blood pressure medication adherence among a sample of 110 African American women 18-45 years of age.

What will I be asked to do?
You will be asked to participate in a research study that will take approximately 1-hour to complete. You will be asked to: complete an intake form providing personal information about you and your health history, seven questionnaires related to the research study, provide a small blood sample to measure your cholesterol level, and lastly, recording of 2-resting blood pressure readings.

Who owns my study information and samples?
If you join this study, you will be donating your samples and study information. You will not receive any compensation if your samples or information are used to make a new product. Since this study only requires one meeting, the likelihood for you to withdraw is minimal; however, if you decide to withdraw from the study prior to obtaining any information or

decline request of the study to use your information once it has been collected, all data will be destroyed and samples will be discarded.

What are the possible risks and discomforts?

The most common risks and discomforts expected in this study are: 50% probability of having a sore finger due to a needle stick to collect a blood sample to obtain your cholesterol level, 10% probability of a sore arm due to the temporary inflation of the blood pressure cuff, which should be alleviated once the blood pressure cuff has been released.

The less common risks and discomforts expected in this study are: disclosure of confidential information, possible emotional distress in completing questionnaires, and discovery of high blood pressure levels.

Rare but possible risks include: minor bruising of the finger from receiving a needle stick and infection due to blood draw. All precautions will be taken to ensure the likelihood of an infection is decreased and minimized by performing proper hand washing before and after the collection of your blood sample.

It is possible that the researchers will learn something new during the study about the risks of being in it. If this happens, they will tell you about it. Then you can decide if you want to continue to be in this study or not. You may be asked to sign a new consent form that includes the new information if you decide to stay in the study.

Will I benefit directly from the study?

This study is not designed to benefit you directly. This study is designed to learn more about factors that enhance hypertension medication adherence in African American women whom are predisposed to worse outcomes due to uncontrolled high blood pressure. The study results may be used to help others in the future by developing interventions that can increase medication adherence.

Will I be compensated for my time and effort?

You will get 25^{00} for completion of the study visit to compensate you for your time and effort. You can decline payment if you are concerned about confidentiality, or you can talk to the study team to see if there are other payment options.

What are my other options?

If you decide not to enter this study, all study discussion will be terminated.

How will you protect my private information that you collect in this study?

Whenever possible, a study number, rather than your name, will be used on study records. Your name and other identifying information will not appear when we present or publish the study results.

Certificate of Confidentiality

There is a Certificate of Confidentiality from the National Institutes of Health for this Study. The Certificate of Confidentiality helps us to keep others from learning that you participated in this study. Emory will rely on the Certificate of Confidentiality to refuse to give out study information that identifies you. For example, if Emory received a subpoena for study records, it would not give out information that identifies you.

The Certificate of Confidentiality does not stop you or someone else, like a member of your family, from giving out information about your participation in this study. For example, if you let your insurance company know that you are in this study, and you agree to give the insurance company research information, then the investigator cannot use the Certificate to withhold this information. This means you and your family also need to protect your own privacy.

The Certificate does not stop Emory from making the following disclosures about you:

- Giving state public health officials information about certain infectious diseases,
- Giving law officials information about abuse of a child, elderly person or disabled person.
- Giving out information to prevent harm to you or others.

Giving the study sponsor or funders information about the study, including information for an audit or evaluation.

Storing and Sharing your Information

De-identified data from this study, including your de-identified genetic information, may be shared with the research community at large to advance science and health. Data from this study may be placed into public databases where, in addition to having no direct identifiers, researchers will need to sign data use agreements before accessing the data. We will remove or code any personal information that could identify you before your information is shared. This will ensure that, by current scientific standards and known methods, it is extremely unlikely that anyone would be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.

Medical Record

If you have been an Emory and Grady Health System patient before, then you already have an Emory and Grady Health System medical record. If you have never been an Emory and Grady Health System patient, you do not have one. An Emory and Grady Health System medical record will be made for you if an Emory and Grady Health System provider or facility gives you any services or procedures for this study.

The results of some study tests and procedures will be used only for research purposes and will *not* be placed in your medical record. For this study, those items include: **Atherosclerotic cardiovascular disease score (ASCVD)**, a metric that estimates 10-year and lifetime risk for coronary death or nonfatal myocardial infarction or fatal or nonfatal stroke calculated from age, sex, race, total cholesterol, HDL cholesterol, systolic blood pressure, blood pressure lowering medication use, diabetes status, and smoking status; **Body Mass Index (BMI),** a measure of body fat based on your reported weight and height, **Cholesterol level** and **Blood pressure**.

Tests and procedures done at non-Emory and Grady Health System places may not become part of your Emory and Grady Health System medical record. Also, if you decide to be in this study, it is up to you to let your other health providers know.

In Case of Injury

OPTION 1: The sponsor may choose not to pay for Subject Injury Costs for any subject, no matter if the subject is insured, or how he/she is insured.

If you get ill or injured from being in the study, Emory and Grady Health System will help you get medical treatment. Emory and Grady Health System and the sponsor have not, however, set aside any money to pay you or to pay for this medical treatment. The only exception is if it is proven that your injury or illness is directly caused by the negligence of an Emory and Grady Health System or sponsor employee. "Negligence" is the failure to follow a standard duty of care.

If you become ill or injured from being in this study, your insurer will be billed for your treatment costs. If you do not have insurance, or if your insurer does not pay, then you will have to pay these costs.

If you believe you have become ill or injured from this research, you should contact Dr. Sandra Dunbar_ at telephone number _404-727-6939. You should also let any health care provider who treats you know that you are in a research study.

Emory and Grady Health System has not set aside any money to pay you or to pay for your treatment if you get ill or injured from being in the study. The only exception to this policy is if it is proved that your injury or illness is directly caused by the negligence of an Emory and Grady Health System or sponsor employee.

If your case meets all four of these requirements and you have private insurance, Emory and Grady Health System will look at the claims for these costs to see if they can be sent to your insurer for payment. Your insurer may be told that you are in a research study and given information about your treatment.

You will have to pay for any costs that the sponsor or your insurer does not pay. The sponsor will pay for any of the costs that are not paid by your insurance provider. The sponsor will not pay for costs like co-payments that your insurer says you have to pay.

Emory and Grady Health System has not set aside any money to pay you or to pay for your treatment if you get ill or injured from being in the study. The only exception to this policy is if it is proved that your injury or illness is directly caused by the negligence of Emory and Grady Health System employee.

Costs
There are no costs, research or standard of care related, associated with the study.

There will be no costs to you for participating in this study, other than basic expenses like transportation. You will not be charged for any of the research activities. If the study procedures result in any medical complications that would not fall under "injury" as discussed above, the cost of treatment for those complications may be charged to you or your insurance.

Withdrawal from the Study
You have the right to leave a study at any time without penalty.

The researchers also have the right to stop your participation in this study without your consent for any reason, especially if they believe it is in your best interest or if you were to object to any future changes that may be made in the study plan.

Authorization to Use and Disclose Protected Health Information

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act and regulations (HIPAA). We refer to all of these laws as the "Privacy Rules." Here we let you know how we will use and disclose your PHI for the single study.

PHI that Will be Used/Disclosed:
The PHI that we will use or share for the main research study includes:

- Date and year of birth

- Medical history and Comorbidities.
- Clinical measurement (BMI & Cholesterol)
- Current Medications
- Blood Pressure reading

Purposes for Which Your PHI Will be Used/Disclosed:
We will use and share your PHI for the conduct and oversight of the research study. We will use and share your PHI to provide you with study related treatment and for payment for such treatment. We will also use and share your PHI to conduct normal business operations. We may share your PHI with other people and places that help us conduct or carry out the study, such as laboratories, data management centers, data monitors, contract research organizations, Institutional Review Boards (IRBs) and other study sites. If you leave the study, we may use your PHI to determine your health, vital status or contact information.

Use and Disclosure of Your Information That is Required by Law:
We will use and disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or abuse of elderly or disabled adults. We will also comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Authorization to Use PHI is Required to Participate:
By signing this form, you give us permission to use and share your PHI as described in this document. You do not have to sign this form to authorize the use and disclosure of your PHI. If you do not sign this form, then you may not participate in the research study.

People Who will Use/Disclose Your PHI:
The following people and groups will use and disclose your PHI in connection with the research study:

- The Principal Investigator, Telisa Spikes, and the research staff will use and disclose your PHI to conduct the study.
- Emory and Grady Health System may use and disclose your PHI to run normal business operations.
- The Principal Investigator and research staff will share your PHI with other people and groups to help conduct the study or to provide oversight for the study.
- Dr. Sandra Dunbar is the Sponsor of the study. The Sponsor may use and disclose your PHI to make sure the research is done correctly and to collect and analyze the results of the research. The Sponsor may disclose your PHI to other people and groups like study monitors to help conduct the study or to provide oversight for the study.
- The research team and the Sponsor may use and disclose your PHI, including disclosure to insurance carriers to administer payment for subject injury.
- The following people and groups will use your PHI to make sure the research is done correctly and safely:
    - Emory and Grady Health System offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Grady Research Oversight Committee, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research.
    - Government agencies that regulate the research including: [Office for Human Research Protections].
    - Public health agencies.
    - Research monitors and reviewer.
    - Accreditation agencies.
    - Office of Nursing Research
    - Dr. Gina Lundberg

- Sometimes a Principal Investigator or other researcher moves to a different institution. If this happens, your PHI may be shared with that new institution and their oversight offices. PHI will be shared securely and under a legal agreement to ensure it continues to be used under the terms of this consent and HIPAA authorization.

Expiration of Your Authorization
Your PHI will be used until this research study ends.

Revoking Your Authorization
If you sign this form, at any time later you may revoke (take back) your permission to use your information. If you want to do this, you must contact the study team at: 404-493-1161.

At that point, the researchers would not collect any more of your PHI. But they may use or disclose the information you already gave them so they can follow the law, protect your safety, or make sure that the study was done properly and the data is correct. If you revoke your authorization you will not be able to stay in the study.

Other Items You Should Know about Your Privacy
Not all people and entities are covered by the Privacy Rules. HIPAA only applies to health care providers, health care payers, and health care clearinghouses. If we disclose your information to people who are not covered by the Privacy Rules, including HIPAA, then your information won't be protected by the Privacy Rules. People who do not have to follow the Privacy rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them.

To maintain the integrity of this research study, you generally will not have access to your PHI related to this research until the study is complete. When the study ends, and at your request, you generally will have access to your PHI that we maintain in a designated record set. A designated record set is data that includes medical information or billing records that your health care providers use to make decisions about you. If it is necessary for your health care, your health information will be provided to your doctor.

We may remove identifying information from your PHI. Once we do this, the remaining information will not be subject to the Privacy Rules. Information without identifiers may be used or disclosed with other people or organizations for purposes besides this study.

Contact Information

Contact [Telisa Spikes, MSN, RN at 404-493-1161)]:

- if you have any questions about this study or your part in it,
- if you feel you have had a research-related injury, or
- if you have questions, concerns or complaints about the research

Contact the Emory University Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

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

If you are a patient receiving care from the Grady Health System and have a question about your rights, you may contact the Office of Research Administration at research@gmh.edu.

Consent and Authorization

TO BE FILLED OUT BY SUBJECT ONLY

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

_____

Name of Subject

_____ _____

Signature of Subject (18 or older and able to consent) **Date** **Time**

TO BE FILLED OUT BY STUDY TEAM ONLY

_____

Name of Person Conducting Informed Consent Discussion

_____ _____

Signature of Person Conducting Informed Consent Discussion **Date** **Time**