# THE EXPERIENCE OF LIVING WITH HYPERTENSION: A NARRATIVE ANALYSIS

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by

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# THE EXPERIENCE OF LIVING WITH HYPERTENSION: A NARRATIVE ANALYSIS

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### DEDICATION

This work is dedicated to God the Alpha and Omega for seeing me through this dissertation journey. I also dedicate the work to my husband, our children, and my mother for their love, patience, support, encouragement, and prayers all the way.

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# LIST OF ABBREVIATIONS

BP: Blood pressure

HTN: Hypertension/High blood pressure

LWBF: Live Well by Faith

PI: Principal Investigator

# THE EXPERIENCE OF LIVING WITH HYPERTENSION: A NARRATIVE ANALYSIS

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#### **ABSTRACT**

Hypertension, an important risk factor for cardiovascular disease, claims about 17.9 million lives every year. There is a largely uncontrolled hypertension epidemic, which results in significant numbers of life-threatening conditions such as myocardial infarction, aneurysm, stroke, end-stage renal disease, congestive heart failure, dementia, and stroke. Adherence to lifestyle modifications and antihypertensive medications is pivotal to hypertension management. Health literacy and social support are germane to medication adherence. The African American population has a disproportionate burden of hypertension. Churches are the livewires of the African American community, advocating multitiered changes that create healthy and supportive living conditions for long-term wellbeing, especially in underserved societies. While many research studies have focused on hypertension, little has been done to explore the illness narratives of African American adults with hypertension. Therefore, the rationale for this narrative study was to generate a deeper understanding of the lived experience and told stories of African American adults with hypertension participating in a faith-based wellness program. Purposeful sampling recruited African American adults (n=15) living with hypertension and participating in a faith-based wellness program. Individual interviews were conducted in person and via Zoom/telephone. Riessman narrative analysis, with the underlying paradigm of social constructionism, was utilized to guide data collection and thematic analysis. Six themes emerged. The overarching theme was self-care behaviors in hypertension management. The main themes were the discovery of the hypertension diagnosis, the realization of hypertension chronicity, the impact of hypertension on everyday life, and social support. Sub-themes were 'Where do I go from here?' and 'social support: not always up for grabs'. Roadblocks to social support included healthcare professionals' historical and current negative attitudes toward people of color. Self-care behaviors played a dominant role in managing hypertension for this group of African American adults who were participating in a faith-based wellness program. Routine medical screenings were critical in the early discovery of hypertension. The chronic nature of hypertension necessitates consistency in lifestyle changes and medication adherence, which may be enhanced by social support and health literacy. Future research should consider the development of interventions that enhance health literacy and social support from the healthcare system, family, and church among African American people living with hypertension.

#### **CHAPTER ONE**

#### INTRODUCTION

# **Background**

Worldwide, cardiovascular disease is the main cause of death, being responsible for losing about 17.9 million lives every year (World Health Organization [WHO], 2020). Hypertension (HTN) is among the 25 leading causes of mortality with a significant contribution to years of life lost (Carnethon et al., 2017). HTN is the leading cause of noncommunicable disease deaths worldwide. The worldwide epidemic of HTN is largely uncontrolled: uncontrolled HTN is majorly responsible for heart attack, stroke, heart failure, and other serious life threats (Burnier & Egan, 2019; Zhou et al., 2018). For example, in Italy, the prevalence of HTN is 25.9% (Tocci et al., 2017) and 44.0% in Latin America. (Lamelas et al., 2019). In as much as being a modifiable risk factor of cardiovascular-related diseases and death, HTN continues to increase disease burden internationally, serving as a trigger to a high health care cost (Athanasakis, 2018; Merai et al., 2016; Writing Group Members et al., 2016).

In comparison, 45.6% of adults (approximately 103.3 million) in the United States with HTN (Benjamin, Virani et al., 2018; Muntner, Carey et al., 2018), only about half of the people with HTN have BP control. Furthermore, approximately 33% (11.5 million people) are not aware of their condition (Merai et al., 2016). Prevalence of HTN among African American people ranks among the highest in the world, with self-reported HTN among more than 12 million African American people (Samanic et al., 2020). African American people have earlier onset and greater severity of HTN than their White

counterparts (American Heart Association [AHA], 2016). Additionally, African American people have greater complications of HTN including heart disease, stroke, and renal disease than other racial/ethnic groups in the US (Muntner, Abdalla et al., 2017). All these factors culminate in higher HTN mortality rates among the African American people.

While HTN is a treatable chronic health condition, there are some challenges associated with achieving high levels of optimal blood pressure (BP) control including adherence to antihypertensive medications and adopting beneficial lifestyle changes such as eating a healthy low-sodium diet and smoking cessation (Merai et al., 2016). Successful control of HTN necessitates self-care behaviors including adherence to antihypertensive medications, lifestyle modifications involving healthy eating, exercise, smoking cessation, and abstinence from alcohol (Bloch & Basile, 2019; Niriayo et al., 2019). Health literacy and social support play a prominent role in the way patients understand how to use the prescribed medications (Mayo-Gamble, & Mouton, 2018) and have been associated with medication adherence (Atukunda et al., 2017).

In general, it is estimated that patients are not adherent to medication 50% of the time. However, up to 80% of the time, patients living with chronic health conditions, including HTN, do not adhere to medications as prescribed (Kleinsinger, 2018; Schoenthaler, Butler et al., 2016). Reasons for medication nonadherence in HTN vary and are complex. The literature denotes the following potential factors contributing to why individuals fail to adhere to medication: forgetfulness, beliefs about illness and treatment, side effects of medications, lack of conviction of medication effectiveness, the complexity of treatment regimens, lack of knowledge regarding HTN and its treatment,

financial difficulties, psychological issues, lack of social support, poor quality of life, duration of therapy, lack of health insurance, medical distrust, poor physician-patient interactions due to racial differences and cultural differences in styles of communication, and underestimating the role of adherence (Brown, Bussell et al., 2016; Ruppar et al., 2017; Derose et al., 2019; Nguyen, Schuiling-Veninga et al., 2017). This aspect of HTN often leads to a lack of effective treatment and management of HTN and a reduction in desirable health outcomes.

In conjunction with a lack of medication adherence, low health literacy has been found to also hinder effective responses to HTN diagnoses. Health literacy has been reported as a strong predictor of medication adherence in many chronic conditions including HTN (Lee et al., 2017; Saglain et al., 2019; Sawkin, et al., 2015). Health literacy, the degree to which individuals are capable to obtain, communicate, process, and understand basic health information and services needed to make appropriate health decisions (CDC, 2021) is inadequate in about half of the people of the United States (Kutner et al., 2006). Low health literacy has been linked to low adherence to antihypertensive medicines and poor health outcomes in chronic conditions, including HTN (Levy & Janke, 2016; Lor et al., 2019). In addition to being able to read, health literacy involves applying information, listening, analytical, and decision-making skills in health-related conditions. Health literacy initiatives and policies in the US have recently focused on enhancing medication adherence. The 2010 Patient Protection and Affordable Care Act underscores health literacy by stressing the importance of clear communication of health information, assurance of equity and culture competencies, patientcenteredness, and high-quality care delivery (National Network of Libraries of Medicine,

2020). With improved and higher health literacy, better HTN management may result and prolong the life of individuals with HTN.

Some studies have shown that social support and interaction between patients and families promote adherence to treatment in chronic health conditions (Gu et al., 2017; Spikes et al., 2019). Social support is defined as perception and actuality that one is cared for, has assistance from other people, and that one is part of a supportive social network (House, 1981). Adequate and improved social support positively affects treatment and adherence of the patients, accelerates the healing process, and increases the quality of life of patients by reducing social isolation (Turan et al., 2019). According to the result of a study by Ofoli and colleagues (2017), social support was a significant predictor of medication adherence of patients with HTN. Therefore, social support is strongly encouraged for individuals with HTN as it can aid in responding appropriately and treating HTN.

The African American population has been disproportionately burdened by HTN evidenced by a higher rate of early onset compared to other racial/ethnic groups (Ortega et al., 2015; Ostchega et al., 2017; Spikes et al., 2019). Significant levels of cardiovascular diseases have existed in the African American population, largely due to HTN (Carnethon et al., 2017). Moreover, approximately half of African American patients with HTN do not adhere to their prescribed medication regimen (Schoenthaler, Butler et al., 2016; Spikes et al., 2019). Suboptimal medication adherence has been linked to poor health outcomes, poor HTN control, increased risk of coronary and cerebrovascular diseases, increased health care costs, increased hospitalization, and higher mortality (Egan & White, 2021; Hamdidouche et al., 2017; Merai et al., 2016;

Vrijens, Antoniou et al., 2017; Zullig & Bosworth, 2017). It is exceedingly important that HTN be studied in African American people to be informed on how to discover, manage, and treat HTN.

### **Faith-based Programs in the African American Community**

Public health promotion efforts within-faith based organizations have become prominent in the last three decades as the organizations can deliver spiritually based information to promote healthy behaviors among members (Johnson-Lawrence et al., 2019). Women are more religious than men globally (Hackett et al., 2016) and in the US, African American women are more religious than African American men (Cox & Diamant, 2018). Faith-based approaches have been found effective in promoting the health of individuals (Tettey, 2018). Faith-based health education programs are programs that incorporate faith and faith practices with applicable methods to address issues or problems individuals may have (Kwon et al., 2017). Particularly, churches serve as an ideal setting to provide essential health resources and information to underserved populations (Tettey, 2018; Thompson et al., 2019). African American faith-based organizations may be pivotal in managing health disparities through wellness programs organized by their health departments (Holt, Graham-Phillips et al., 2017). Hence, faithbased programs and interventions implemented into HTN-care, especially in African American communities, can strengthen the treatment of HTN symptoms among individuals diagnosed with the disease.

To this end, strategies to mitigate blood pressure control in African American population, are needed. Furthermore, since health literacy and social support have been

associated with medication adherence, strategies to enhance health literacy and social support are foundational. Although there are many studies on medication adherence in HTN (Holt, Rung et al., 2014; Krousel-Wood et al., 2009; Lenahan et al., 2013; Li et al., 2016; Náfrádi et al., 2016; Ramil et al., 2012; Sawkin et al., 2015; Schoenthaler, Chaplin et al., 2009; Nguyen, Schuiling-Veninga et al., 2017; Solomon et al., 2015; Vrijens, Antoniou et al., 2017), very few studies have been conducted that focus on the experience of living with HTN among African American people participating in a faith-based program. A qualitative research study using a narrative analysis approach was conducted to better understand the lived and told stories of African American adults with HTN.

#### **Purpose of Study and Research Question**

The purpose of this narrative analysis was to generate a deeper understanding of the lived experience and told stories of African American adults with HTN (Peterson, Baker, & McGaw, 2010) who participated in a faith-based health promotion program. Such an understanding contributes to the body of knowledge in public/community health and nursing. Through the understanding gained from the study, a voice was given to the participants and the participants' experiences were presented to the readers in a wider audience. Findings from this study may be used to influence policies, which may help to provide better care for the African American population thus reducing health disparities, morbidity, and mortality. The research question that guided this study was:

What is the experience of living with HTN for African American adults participating in a faith-based wellness program in mid-Missouri?

### **Locating the Researcher in the Research**

Conducting narrative analysis requires the researcher to identify and examine individual biases and prior beliefs, and co-construct peoples lived and told stories.

Narrative being a method of qualitative research may be used to interpret the meaning people give to their world to gain its understanding (Joyce, 2015). The principal investigator (PI) of this study is a Registered Nurse with practice experience both at the local and international levels. Furthermore, the PI has a Master of Science in Nursing with a specialization in community health nursing. The PI also took a course titled 'Participatory approaches for health and health systems' in the 'Participatory health research' graduate certificate program during the doctoral training. The course was aimed at preparing researchers for researching the community. These experiences and training have adequately prepared the PI for this research.

The PI's advisor engages in academic-community research with an American-based nonprofit organization and Fundación Enciende Una Luz -FEUL' (Light a Candle Mission) in the Dominican Republic (DR) in the Jonas Batey HTN program. Established in 2009, the FEUL is a DR non-governmental organization and provides health education, health promotion, and empowerment to people living in poor, underserved rural bateyes (Light a candle mission, 2020). Jonas batey HTN program was established in 2016 to address HTN in the DR bateyes. The PI had an opportunity to go with her advisor to DR in Winter 2019 on research practicum to conduct a qualitative study among the program's promotoras. The promotoras are trained lay health workers in the batey community and play a key role in enhancing health promotion and disease prevention (Conley, 2019; Parra-Medina & Hilfinger Messias, 2011). The DR promotoras work

closely with the NGO in the program to coordinate mobile clinic visits to 11 bateyes every 3 months.

The purpose of the qualitative study conducted in the DR was to explore the promotoras' perception of barriers and facilitators to medication adherence among adults with HTN in DR bateyes. Institutional review board (IRB) approval was sought and obtained from the University of Missouri Health Sciences IRB. The PI utilizing purposive sampling recruited six promotoras and collected data with the assistance of Spanish-and Creole-speaking translators through individual interviews. The interviews were audio-taped, transcribed verbatim in Spanish. The transcripts were then translated to English and analyzed using thematic content analysis. Findings of the study showed that the promotoras felt they were making a positive impact on the health of the residents in their respective batey communities. The promotoras were also enthusiastic about the mobile HTN program. An identified barrier to medication adherence was promotoras' inability to identify HTN cases and enhance adherence by monitoring BP between mobile clinics. Facilitators to medication adherence were consistent, reliable delivery of HTN medications, and promotoras assisting patients in remembering to take their medications. The PI's community health nursing specialization and DR research practicum informed this study. Overall, the practicum experience opportunity afforded the PI to actively participate as a researcher in HTN research.

Additionally, the PI has cared for patients in Nigeria and the United States with HTN, stroke, HTN/mental health conditions, and other types of cardiovascular diseases. During all of the PI's nursing practice, she realized that some of the patients could not take the antihypertensive medications as prescribed due to some identified factors

including costs, side effects, and access. As a result, some of the patients developed complications including myocardial infarction and renal failure. The PI has also discussed with a colleague and two relatives diagnosed with HTN who could not take antihypertensive medications as prescribed due to costs, lack of transportation, and co-occurring side effects.

The PI's beliefs are as a result of her training and experiences, that although HTN may be genetic among the African American people, the condition can be controlled and/or prevented. The PI believes that health care practitioners must listen to people with HTN to be able to know how to best manage the condition. Based on these reasons, the PI elected to conduct a narrative analysis of lived and told stories of African American adults with HTN.

# Significance of Study to Nursing and Healthcare Innovation

Extant literature shows that BP control is poor among African American people (Yoon et al., 2015; Writing Group Members et al., 2016). Self-care behaviors play a very significant role in the management of HTN. The role of health literacy, medication adherence, and social support especially from a church-based wellness program like LWBF are well documented in the literature (Campbell et al., 2007; Johnson-Lawrence et al., 2019; Lee, et al., 2017; Mayo-Gamble & Mouton, 2018). Even though the study participants reported taking antihypertensives, the challenges encountered prevented adherence to the medication use, and engagement in exercise and a healthy diet. The study findings show that consistency of self-care is key to BP control among African American people with HTN. Further, the involvement of churches in wellness programs,

especially in the African American community, may go a long way in ensuring optimal health of the vulnerable population and by extension the society at large. Churches can organize wellness programs including BP monitoring during church events, and health fairs for the congregants and people in the surrounding community. The wellness programs will help screen for HBP, promote early referral and management of people at risk, and consequent reduction of morbidity and mortality rates among African American adults.

#### **Definition of Terms**

Experience: the fact or state of having been affected by or gained knowledge through direct observation or participation (Daher et al, 2017)

Health literacy: The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions (CDC, 2021).

Hypertension: A systolic pressure of at least 130mmHg and a diastolic level of at least 80 mmHg (Whelton et al., 2018; LeFevre, 2018)

Medication adherence: The extent to which a patient's behavior corresponds with the prescribed medication dosing regime, including time, dosing, and interval of medication intake (Gast & Mathes, 2019).

Social support: Resources provided by other people including family, friends, and support groups concerned about the patients' illness condition and creates a positive feeling and self-esteem (Asgari et al., 2019).

#### **CHAPTER TWO**

#### LITERATURE REVIEW

Cardiovascular diseases, including HTN, are the leading causes of death globally (WHO, 2021) accounting for 45% of deaths (Burnier & Egan, 2019). HTN is a major public health challenge since it is a major risk factor for heart disease, kidney failure, eye problems stroke, and premature death worldwide (WHO, 2021). HTN is the largest worldwide epidemic disease constituting a threat to health in developed countries (Asgari et al., 2019). The number of adults living with HTN has increased from 594 million in the year 1975 to over 1.13 billion, largely from increase low-income and middle-income countries (WHO, 2020; Non-Communicable Disease Risk Factor Collaboration, 2017). The worldwide prevalence of HTN is on increase and projected to be 1.56 billion by the year 2025 (Niriayo et al., 2019). Mills et al. (2016)'s systematic analysis of 90 countries revealed that 31.1% of the world's adults had HTN, with 28.5% in high-income countries and 31.5 % in low- and middle-income countries in 2010. In 2015, Russia, China, Indonesia, and the US accounted for over 50% Disability-Adjusted Life Years (DALY) associated with SBP of about 110 to 115 mmHg (Forouzanfar et al., 2017). HTN is referred to as "the silent killer" due to the asymptomatic and persistent nature of the condition (Abu et al., 2018). HTN is ubiquitous and affects people all over the world.

HTN is the most prevalent chronic condition affecting about half of the US adult population (CDC, 2020). HTN is one of the leading cardiovascular disease risk factors affecting 120 million Americans based on the new American College of Cardiology/American Heart Association (AHA) guidelines (Benjamin, Muntner, et al.,

2019; Muntner, Carey, et al., 2018; Carey et al., 2018) resulting in billions of dollars related to health care costs (J. Burns et al., 2019). Based on the Eighth Joint National Committee (JNC 8)/ACC/AHA guidelines, normal blood pressure (BP) is systolic BP (SBP) of less than 120 mmHg and diastolic BP (DBP) of less than 80 mmHg, elevated BP is SBP of 120-129 mmHg and less than 80mmHg, and HTN starts from SBP of 130 mmHg and DBP of 80 mmHg (Whelton et al, 2018). HTN affects almost one-third of Americans aged  $\geq 18$  years (about 75 million people) (Yoon et al., 2015). Disturbingly, 33% (11.5 million people) are not aware of the HTN, and only about half of people with HTN have controlled BP (approximately 35 million persons) and about 1 in every 5 of the people are aware of their condition but are not being treated (Merai et al., 2016). HTN being a chronic disease is associated with medication nonadherence, which presents as a major obstacle to HTN management in many patients. Many factors associated with not using medications as prescribed include non-affordability of medications (Gellad, 2007; Appiah et al, 2020), being on multiple medications (Burnier, Polychronopoulou, et al., 2020), forgetfulness, race, and low health literacy (Schoenthaler, Butler, et al., 2016).

# **HTN Prevalence in the African American Adult Population**

Despite advancements in awareness, treatment, and control rates among many racial groups, African American population continues to experience a high level of HTN-related diseases resulting in health disparity (Musemwa & Gadegbeku, 2017). In the U.S., research studies have shown a higher prevalence of HTN in the African American population compared to White people (Buckley et al., 2016; Fryar et al., 2017; Hou, Aradine, et al., 2020; Merai et al., 2016; Ortega et al., 2015; Schober et al., 2020; Schoenthaler, Butler, et al., 2016; Spikes et al., 2019; Yoon, et al., 2015). African

American people represent 13.3% of the US population and are the second-largest racial/ethnic minority (Carnethon et al., 2017) after Hispanic/Latino peoples. In comparison with their white counterparts, African American people are more likely to develop HTN and not have their BP under control (Fryar et al., 2017). African American people are also at a higher risk of HTN-related complications (Muntner, Abdalla, et al., 2017) including stroke compared to White people (Skolarus et al., 2018). HTN is responsible for 50% of racial differences in the mortality rate between African American people and white people in the US (Musemwa, & Gadegbeku, 2017). Premised on the findings of the American College of Cardiology/American Heart Association 2017 threshold for HTN, the findings of a study by Chen et al. (2019) showed that the cumulative lifetime risks for HTN were 86.1% for African American men, 83.8% for White men, 69.3% for White women, and 85.7% for African American women.

The African American population has a disproportionately higher burden of HTN, higher rate of early-onset, and more uncontrolled BP as compared to other racial/ethnic groups (Fryar et al., 2017; Ortega et al., 2015; Spikes et al., 2019) and more dangerous than in White people (Benjamin et al., 2018; Whelton et al., 2018). One of the greatest public health challenges in the US is uncontrolled HTN in the African American population culminating in health disparity (Musemwa & Gadegbeku, 2017; Whelton et al., 2018). The age-adjusted prevalence of HTN is 42% vs 28% for African American people and White people respectively and thus resulting in the highest prevalence of HTN among African American people in the US (Schoenthaler, Butler, et al., 2016; Carnethon et al., 2017). African American people have a 1.8 times greater rate of fatal stroke, a 1.5 times greater rate of heart disease and death, and a 4.2 times greater rate of

end-stage renal disease than White people (CDC, 2000). According to the findings of the 2015-2016 National Health and Nutrition Examination Survey (NHANES) study, provider diagnosis of HTN among the African American people was 48%, and undiagnosed HTN was 15% (Commodore-Mensah et al., 2016).

In Missouri, over 61% of people have at least one chronic condition with 30.9% of the population having HTN (State of Childhood Obesity, 2020). The age-standardized prevalence of HTN in Missouri was highest in people aged 65 and above (60.5), in households with income less than \$15,000 (37.9), and less than a high school education (35.4) (Samanic et al., 2020). Moreover, in Missouri, the prevalence of HTN in African American people (40%) is significantly higher than the prevalence of HTN in White people (29%) (Samanic et al., 2020)

#### **Risk Factors for HTN**

HTN has been associated with age, gender, smoking, family history, marital status, eating late, family history of diabetes mellitus, stressful situation, obesity, and insomnia, (Anto et al., 2020; Nyuyki, Ngufor, et al., 2017). The findings of a study conducted in Cameroon (Menanga et al., 2016) showed that 63.6% of females were hypertensive with a mean age of 61 years. The findings of a study conducted in Iran showed that HTN was more prevalent in smokers than nonsmokers (Abtahi et al., 2011). In the US HTN has been associated with smoking, obesity, excess alcohol, a sedentary lifestyle, high intake of sodium, and low intake of potassium (CDC, 2020).

HTN health outcomes have also been associated with self-care behaviors (Ademe et al., 2019; Gebremichael et al., 2019; Maciejewski et al., 2014). Self-care means the

ability of individuals, families, and communities to promote and maintain health, prevent disease and cope with illness and disability with or without the support of a health care provider (WHO, 2020). Godfrey et al. (2011) reported a content analysis of 139 definitions identifying seven components of self-care. The International Self-care Foundation (ISF) therefore created and utilizes a description of self-care known as "Seven Pillars of Self-Care" (International Self-Care Foundation - ISF, 2020). The seven pillars are as follows:

- (i) knowledge & health literacy includes the capacity of individuals to obtain and health information to make useful health decisions.
- (ii) mental well-being, self-awareness & agency includes knowing one's body mass index, BP, and engaging in health screening
- (iii) physical activity engaging in physical activity of moderate intensity such as walking or cycling.
- (iv) healthy eating intake of a nutritious balanced diet consisting of fruits, vegetables, legumes, whole grains, nuts, unsaturated fats, and reduced sodium.
- (v) risk avoidance or mitigation reducing alcohol, quitting tobacco,vaccination, using sunscreen and practicing
- (vi) good hygiene teeth brushing, washing food, and regular hand washing
- (vii) rational and responsible use of products, services, diagnostics, andmedicines being aware of dangers and using as necessary (ISF, 2020).

From the self-care pillars, it is apparent that self-care behaviors are important activities that an individual engages in to improve health or prevent disease and include

lifestyle modifications involving low-sodium low-fat diet, weight reduction, regular medical checks, self BP checks, exercise, reducing stress, not smoking, alcohol reduction/abstinence, and adherence to antihypertensive medications (Han et al., 2014; Niriayo et al., 2019). Self-care in HTN is an active process that necessitates knowledge, attitude, determination, commitment, discipline, empowerment, and self-efficacy (Balduino et al., 2013). Research studies showed that self-care practices among patients with HTN were germane to the control of BP (Kim et al., 2014; Maciejewski et al., 2014; Ademe et al., 2019).

#### **Medication adherence**

Medication adherence refers to the degree to which a patient's behavior matches the prescribed medication dosing regime, including time, dose, and interval of taking medication (Gast & Mathes, 2019). Apart from also being the process by which patients take medications as prescribed, medication adherence has also been defined as a ratio of the number of drug doses taken to the number of doses prescribed over a given time (Burnier, 2018; Morrison et al., 2015; Vrijens, De Geest, et al., 2012). Adherence to antihypertensive medications is germane to controlling HTN (Abegaz et al., 2017) as high adherence to antihypertensives has been associated with HTN control (Chang et al., 2018). Medication adherence is effective in managing HTN.

There are different methods of assessing medication adherence. The methods are categorized into two: direct and indirect methods. The direct method is measuring levels of medication/metabolite. The indirect methods include pill counts, self-reports (including questionnaires and visual analog scales), and electronic monitoring systems

(Anghel et al., 2019). For the direct method, measuring drug/metabolite levels is used to determine the concentration of the medication/metabolite and is beneficial, being accurate, objective, and evidence to support that the patient has taken the medication. However, the direct method is expensive, invasive, and subject to individual differences. For the indirect methods, pill count is used in determining the number of doses missed and beneficial, being a simple method and is mostly used in clinical trials. However, the method does not show evidence of ingesting the medication. Electronic databases are also used to determine the medication possession ratio (MPR) based on the proportion of days covered (PDC). The method is easy to use, helps to identify non-adherent patients, inexpensive, non-invasive, and patients are not aware of being monitored. Although the method proves that medication is dispensed, there is no proof of medication ingestion. The self-reported method includes questionnaires and analog scales interpreted based on pre-established cut-off points. Although the method is simple to use and not expensive, the method is subjective, being influenced by recall bias and the risk of overestimation of adherence levels. Electronic monitoring systems like Medication Event Monitoring System, MEMS, are used to determine the dosing regimen and the overall percentage of doses the patient has taken (Lam & Fresco, 2015). Although the method is objective and is one of the most accurate methods, there is no evidence to support that the patients have taken the medication (Anghel et al., 2019; El Alili et al., 2016). Moreover, medication adherence level can also be measured using Morisky Medication Adherence Scale (MMAS), Morisky Levine Green, Medication Adherence Report Scale (MARS), pharmacy refills, serum uric acid, and urinary chlorthalidone (Alison Philips et al., 2013; Conn et al., 2016; Solomon et al., 2015).

Medication nonadherence has been an important issue among African American adults with HTN (Bazargan, Smith, Yazdanshenas, et al., 2017). HTN is a public health challenge and a threat, especially in African American community. Many factors contribute to the disproportionate burden of HTN among the African American people. Lifestyle changes including smoking cessation and dietary changes, exercise, and social support from families and churches have been found helpful in the management of HTN. As a chronic health issue, HTN necessitates long-term management including adherence to prescribed medications regimen. Medication adherence has been a challenging issue in HTN (Vrijens, Antoniou, et al., 2017). There can be issues with non-adherence to medication at initiation, implementation, and/or untimely discontinuation (Vrijens, De Geest, et al., 2012). A recent meta-analysis showed a global prevalence of non-adherence of 45.2% (Abegaz et al., 2017). The results of the study are in tandem with another study conducted among patients diagnosed with HTN in low-middle income nations of Cameroon and Pakistan, where non-adherence prevalence was 33.3%, and 61.1% (Adidja et al, 2018; Saqlain et al., 2019), and 34.2% in China, a developing middle-income nation (Hou, Zhang, et al., 2016). Approximately 46% of African American patients with HTN do not adhere to their prescribed medication regimen (Schoenthaler, Butler, et al., 2016; Spikes et al., 2019). In comparison with the White counterparts, African American people with HTN are 1.81 to 4.30 times less likely to adhere to their antihypertensive medications (Schoenthaler, Butler, et al., 2016). Poor adherence to prescribed antihypertensive medications has been identified as a great contributor to poor control of BP control among African American people (Schoenthaler, Butler, et al., 2016).

Facilitators of medication adherence among African American adults with HTN have been identified. HTN can be managed through well-known lifestyle interventions including weight loss, lowered daily dietary salt intake, increase physical activity; and adherence to prescribed medications (Buis et al., 2019). Facilitators of medication adherence include routines, health literacy, reminders, and social support, (Meinema et al., 2015; Rimando, 2015; Schober et al., 2020). There is a growing body of evidence on social support in the management of chronic diseases. Social support refers to resources provided by other people including family, friends, and support groups concerned about the patients' illness condition, and creates a positive feeling and self-esteem (Asgari et al., 2019). Social support has been categorized into four namely informational, instrumental, appraisal, and emotional support - caring, love, trust, and empathy (House, 1981). Social support has been found to have a positive influence on medication adherence of patients with HTN (Turan et al., 2019) and can enhance adherence to prescribed treatment regimens (Osamor, 2015). Social support also contributes immensely to improved health outcomes, especially in facilitating dietary changes (Nyaaba et al., 2019). According to the result of a qualitative systematic review by Whitehead et al. (2018), families provide social support by playing a key role in providing a conducive environment in the self-management of chronic conditions among adult family members. Strong support from family has been associated with controlled BP (Ojo et al., 2016). The lack of social support leads to adjustment problems, difficulties in treatment, and a delayed recovery process (Turan et al., 2019). Adequate and improved social support positively affects treatment and adherence of the patients thereby accelerating the healing process (Turan et al., 2019).

### **Health Literacy**

About 80 million US adults have basic or below basic health literacy skills (Mayo-Gamble & Mouton, 2018). Health literacy has been identified as a social determinant of health with regards to the impact on health outcomes (Loan et al., 2018; Rowlands et al., 2017). Low levels of health literacy are associated with both males and females (Clouston et al., 2017; Javadzade et al., 2012), few years of schooling, older age (Cox et al, 2017; Jessup et al., 2017), health inequality, that is, systematic health differences among groups of people (Logan et al., 2015), and lower household income (Nyman et al., 2018). Low levels of health literacy are also related to poorer healthrelated knowledge and comprehension, including the ability to read and understand medication labels, and health messages (Berkman et al., 2011). Low health literacy has also been associated with a high mortality rate. According to the findings of an English longitudinal study of aging among 7731 adults by Smith et al. (2018), mortality rates were 30.3% in the low health literacy groups and 14.3% in the high health literacy group. The findings of a systematic scoping review by Yuen et al (2018) showed that the prevalence of limited health literacy in caregivers of patients with chronic diseases ranged from 0% to 52.5%, and low caregiver health literacy was associated with poorer care recipient self-management behaviors; increased use of health services by care recipient; and high caregiver burden. All these factors show that health literacy is not dependent on sex but is negatively influenced by low education, low income with resultant health complications, and high fatality rate.

Health literacy is assessed using different tools. Measures of health literacy include the Short Test of Functional Health Literacy in Adults (STOFHLA) (Gerber et

al., 2010), Rapid Estimate of Adult Literacy in Medicine (REALM) (Ingram & Ivanov, 2013; Mayo-Gamble & Mouton, 2018; Schoenthaler, Chaplin, et al., 2009), Single Item Literacy Screener (SILS) to measure health literacy (Al-Ruthia et al., 2017) and HTN Health Literacy Scale (Kim et al., 2012). The researchers have used the health literacy measures to conduct studies in the field of health literacy (Al-Ruthia et al., 2017; Gerber et al., 2010; Ingram & Ivanov, 2013; Mayo-Gamble & Mouton, 2018; Schoenthaler, Chaplin, et al., 2009).

Research has consistently found differences in health literacy among African American people, typically lower, compared to other groups. In a non-randomized cohort trial conducted in North Carolina by Halladay et al. (2017) the association between health literacy and reduction of BP was higher (77%) among African American adults than the White adults (52%, p < 0.001). with uncontrolled HTN. In another study conducted by Gerber et al. (2010), African American people were found to have lower health literacy (26.7%) than white people (81.5%, p < 0.001). Additionally, a study conducted by Ingram and Ivanov (2013) on health literacy and antihypertensive medication regimen adherence among African American adults with HTN, found that about 13% of the participants had low health literacy. Lastly, a cross-sectional study by Bosworth et al. (2006) among 608 African American adults with HTN in Durham, North Carolina, found that 45% of the African American participants in the study had below 12th-grade health literacy. In sum, African American people historically have lower health literacy due to many contributing factors. The lower levels of health literacy consequently make managing the public health concern of HTN in the African American community more difficult.

#### **Health literacy and Medication Adherence**

Research studies have shown a significant relationship between higher medication adherence and higher health literacy, higher self-efficacy, the effectiveness of medications, beliefs about the severity of HTN, and low perceived barriers to adherence (e.g., side-effects) (Mayo-Gamble & Mouton, 2018; Schoenthaler, Butler, et al., 2016; Saqlain et al., 2019). According to the findings of a cross-sectional study with Pakistan adults with HTN, adequate health literacy was found to be among the independent predictors of medication adherence in patients with HTN (Saqlain et al., 2019). However, low health literacy has also been associated with poorer adherence to hypertensive medications (Ghembaza et al., 2014; Jankowska-Polańska et al., 2016; Wannasirikul et al., 2016; Roldan et al., 2018). Patients with low health literacy are more likely to get confused about their medication regimen (Mayo-Gamble & Mouton, 2018). Health literacy is instrumental in managing health and being able to follow provider instructions such as dosage, duration, frequency, and warning labels (Conn et al., 2016; Geboers et al., 2015; Wali et al., 2016).

According to findings of a study conducted by Mayo-Gamble and Mouton (2018) among African American adults with HTN in the greater Washington DC area, health literacy was a positive determinant of medication adherence. Study participants with adequate health literacy were more likely to report not forgetting to take their medications (60.8%) than the participants with limited health literacy (56.3%;  $\chi$ 2 (5) = 15.9, p =.007). Participants with adequate health literacy were also more likely to report taking medication as instructed (84%) than the participants with limited health literacy (78.8%;  $\chi$ 2 (5) = 10.31, p = .036). Findings from this study suggest that health care

providers should assess health literacy levels when initiating HTN treatment (Mayo-Gamble & Mouton, 2018).

When patients believe being at higher risk of complications, the patients demonstrate higher adherence to medications (Al-Noumani et al., 2019; Kamran et al., 2014). Adherence to antihypertensive medications is significantly related to improved control of SBP (Yue et al., 2015). According to the findings of the first National Assessment of Adult Literacy (2003), only 12% of US adults had proficient health literacy; 24% of African American adults had below basic health literacy and only two percent had proficient literacy (US Department of Health and Human Services, 2008). The results of the mentioned studies illustrate the importance of health literacy concerning favorable health outcomes, specifically medication adherence.

# **Barriers to Medication Adherence among African American adults with HTN**

Aside from being a great challenge and preventing successful treatment of HTN (Solomon et al., 2015), barriers to medication adherence in the African American community include poor adherence to antihypertensive medications, drug-resistant HTN, increased risk of coronary and cerebrovascular diseases, increased health care costs, increased hospitalization, and higher mortality (Cutler et al., 2018; Hamdidouche et al., 2017; Lee et al., 2017; Vrijens, Antoniou, et al., 2017; Zullig & Bosworth, 2017). African American people are less likely than White people to report medication adherence, lifestyle, and behavioral changes needed for a proper response to an HTN diagnosis (Benjamin et al., 2018). According to the findings of a systematic review by Cutler et al. (2018), the yearly economic cost of non-adherence per patient in cardiovascular diseases including HTN ranged between \$3,347 and \$19,472.

Findings from the literature show factors that may influence non-adherence to antihypertensive medications. These factors can be divided into five categories namely social and economic factors, therapy-related factors, condition-related factors, patientrelated factors, and health care system-related factors (Gast & Mathes, 2019). Social and economic factors non-adherence to medications include poor socio-economic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, lack of access to a treatment center or pharmacy, high cost of transportation and high cost of medication, race, culture, beliefs about illness and family dysfunction. Patient-related factors include race, age, gender, socioeconomic status, forgetfulness, (psychosocial) stress, non-acceptance of disease, misunderstanding of treatment instructions, anxiety, polypharmacy, medication cost, education, presence of comorbidities, medical status, social support, societal culture (Buckley et al., 2016; Calderón-Larrañaga et al., 2016; Gu et al., 2017; Gupta et al., 2017; Neiman et al., 2017; Saglain et al., 2019). Healthcare team and system-related factors include poorly developed health services, inadequate reimbursement by health insurance plans, poor overworked health care providers and lack of knowledge on adherence, quality of the relationship between patient and physician, and complexity of treatment regimens (Cyrus et al., 2019).

Condition-related factors include illness-related demands encountered by the patients namely severity of symptoms, progression, and severity of the disease, and availability of effective treatment. Therapy-related factors include complex medical regimen, duration of treatment, previous failure of treatment, and side effects of medications. Asymptomatic nature of HTN, belief about effectiveness or benefits of

medications, bad taste, deleterious effects, and depression have also been associated with lower medication adherence (Al-Noumani et al., 2019; Kamran et al., 2014; Spikes et al., 2019; Yang et al., 2016). Other reasons for medication non-adherence in HTN include beliefs about illness and treatment, lack of knowledge regarding HTN and its treatment, psychological issues, poor quality of life, and underestimation of the role of adherence (Al- Ramahi, 2015; Enriquez & Conn, 2016; Sawkin et al., 2015; Zullig & Bosworth, 2017). A recent meta-analysis showed a global prevalence of non-adherence to antihypertensive medications of 45.2% (Abegaz et al., 2017). According to the findings of a nationwide study in the U.S., Ritchey, and colleagues (2016) found that 26.3% (4.9 million) of the participants were considered non-adherent to antihypertensive medications, and non-adherence to antihypertensive medications in the Midwest was 22.8%. These factors have been documented as important factors that hinder medication adherence in controlling HTN.

Many factors can be correlated to nonadherence to antihypertensive medications (Rimando, 2015; Bazargan, Smith, Yazdanshenas et al., 2017). The results of a study among African American adults by Bazargan, Smith, Yazdanshenas and colleagues (2017) showed that co-payment for drugs, memory deficits, Medication Regimen Complexity Index (MRCI), and medication-related knowledge were all associated with adherence to medication dosage regimen. Participants with a higher level of knowledge about therapeutic purpose and knowledge about dosage regimen of their medications were seven times more likely to adhere to frequency and dose of medications.

Participants with a low complexity index were twice more likely to adhere to the dosage regimen of their medications, compared with participants with a high drug regimen

complexity index (Bazargan, Smith, Yazdanshenas, et al, 2017). Not many studies were found that reported on medication adherence among individuals living with HTN in Missouri. The findings of one study among individuals with chronic obstructive pulmonary disease in Missouri showed that only 28.7% of patients adhered to at least one medication (Bollmeier et al., 2019). However, there is a dearth of studies with a particular focus on health literacy as a determinant of medication adherence (Kuo et al., 2016; Miller, 2016) among African American adults with HTN.

In addition to the previously discussed factors, there are some U.S. historical and current factors that may impact medication adherence. The factors include the Nazi atrocities in World war II (leading to the formulation of the Nuremberg Code), the Tuskegee Syphilis Study, and experiences of African American women and children. After World War ended in 1945, 'The Doctors' Trial' took place in 1947 as 23 physicians were tried for grotesque experiments carried on European Jews who were prisoners of war. Sixteen of the physicians were found guilty of a crime against humanity and were given jail and death sentences. The trial verdict also led to the formation of the Nuremberg code targeted at protecting human rights (Jarmusik, 2019).

In the Tuskegee study that began in 1932 and lasted for 40 years, poor uneducated African American men in Alabama infected with syphilis were recruited to participate in a study that would treat their 'bad blood' (Prather et al., 2018; Spence and Oltmanns, 2011). Instead of treating the men when the treatment was available, medical doctors deliberately left the men untreated to study the natural course of syphilis against the men's knowledge. Coupled with the fact that the men were experiencing syphilis-associated morbidity and mortality, some of the men's wives and children acquired

syphilis and suffered congenital syphilis-related complications respectively (Prather et al., 2018). The undue advantage and experimental atrocity have instilled anger, mistrust, and fear in the heart of many African American people (Barrett et al., 2017; Rosenthal & Lobel, 2011).

Henrietta Lacks's story is an example of abuse and maltreatment of African American people in conducting research and an appalling disregard for the three fundamental ethical principles of respect for persons, beneficence, and justice (Jones, Vyhlidal, et al., 2017; Skloot, 2017). Henrietta Lacks was an African American woman diagnosed with advanced cervical cancer and received treatment at John Hopkins Hospital, Maryland. While undergoing treatment, a scientific researcher obtained samples from Henrietta's aggressive and rapidly growing cancerous cervical tissue without her consent, though not required at that time. The samples were used to establish an immortal cell line, HeLa cells, that resulted in significant advancement in translational research and novel medical products including the Polio vaccine. Long after the cells were harvested, and Henrietta passed away, Ms. Lacks' family learned of the cells' use in medical research and immense wealth generated for other people. The U.S also has a pathetic history of forced and undisclosed sterilization of women of color. An example is Fannie Lou Hamer, a Black woman who went into a hospital for surgical removal of a uterine tumor. Doctors performed a complete hysterectomy on her without any medical indication, knowledge, or consent (George et al, 2014; Rosenthal & Lobel, 2011). The experiences of the women demonstrated a violation of the ethical principle of autonomy.

Furthermore, in the past two decades, unethical medical research by a prestigious U.S. university was conducted among African American boys in a study that

hypothesized a genetic etiology of aggressive behavior (Scharff et al., 2010). The researchers through monetary incentives convinced parents to enroll their sons in a study that was inimical to the sons' health. The study involved withdrawal from every medication (including asthma medications), taking a low protein diet, an overnight stay with parents not around, withholding of water, hourly blood draw, and administering fenfluramine which increases serotonin levels and is associated with aggressive behaviors. White American children were not enrolled in the study (Washington, 2006).

Current treatment-related factors also contribute to a lack of trust between African American people and healthcare providers. Findings of the Institute of Medicine (2003) showed that African American people are less likely than minority/ ethnic groups to be treated for diseases like diabetes, cardiovascular disease, and cancer. For instance, African American people are less likely to undergo bypass surgery and pharmacological therapy even when needed (Nelson, 2002). African American people regardless of social class also experience discrimination and more likely to receive less quality care compared with the White American people (Kennedy, 2013). African American people, therefore, drew analogies from their own experience and the harrowing experience of the Jews (Webb, 2019) and do not want to be treated as guinea pigs (Jones & Jablonski, 2014). The historical and current maltreatment and research atrocities that had been committed against the African American people by healthcare providers in the afore-mentioned studies have led to the distrust, skepticism, and fear with resultant poor adherence/nonadherence to the treatment process including the use of antihypertensive medications (Forsyth et al., 2014; Gamble, 1997; Jones & Jablonski, 2014; Nelson, 2002).

The PI conducted an integrative review to explore published literature that has specifically examined the impact of health literacy level on medication adherence among African American adults diagnosed with HTN (Oyewusi & Enriquez, 2020). The review findings showed that evidence to affirm that higher health literacy results in better medication adherence was minimal as few studies specifically targeted the African American adult population. Most studies in the review had small numbers of African American participants demonstrating an underrepresentation of the African American people in research studies. This may directly and/or indirectly hamper African American health literacy. Importantly, this may strongly affect HTN health-related outcomes among African American people.

## **Community-Engaged Research in African American community**

One aspect of community health research that has significantly impacted academic-community research geared towards regaining trust in community settings has been community-engaged research. Community-engaged research (CEnR) is an approach for researching similar interests requiring cooperation, negotiation, partnership development, commitment, and collaboration between academic researchers and the community to address community issues for improved health (Rhodes et al., 2018). Community-engaged research identifies and builds on community strengths and may be used with quantitative, qualitative, and mixed methods (Balls-Berry & Acosta-Pérez, 2017; Moore de Peralta et al., 2020). Community-engaged research exists on a continuum depending on the intensity of engagement ranging from outreach and little collaboration to shared leadership whereby the community and academic researchers are equal partners all through the research process (Eder et al., 2018; London et al., 2020).

A few studies incorporating CEnR methodology have included African American participants and have supported the effectiveness of CEnR in public health research in reducing health inequities, promoting medical health literacy and outcomes of African American peoples (Blanks et al., 2016; Eder et al., 2018; Nasser & Ferdinand, 2018; Wallerstein et al., 2020). Blanks et al. (2016) utilized CEnR to develop a health education intervention targeted at promoting weight loss, and knowledge about healthy lifestyles among African American adults in South Carolina. The study findings showed improved knowledge about nutrition, higher engagement in exercise, and reduced BP, weight, and body mass index. In a review article on the impact and effectiveness of community interventions for controlling HTN among African American people, CEnR and out-of-office BP measurements facilitated HTN control (Nasser & Ferdinand, 2018). The program promoted inclusive and fruitful relationships in the academic community partnership.

## Faith-Based Wellness Programs in the African American community

Faith-based organizations, including churches, have been known to serve as conduits for health promotion and research in different communities (Campbell et al., 2007). The organizations are at the forefront of health promotion and wellness programs particularly in African American communities and have great potentials to influence the health behaviors of members at multilevel of change to reduce health disparities.

Research supports the involvement of African American, faith-based organizations and improvement in community health outcomes associated with HTN. Frew et al. (2015) conducted a randomized trial among African American adults from six different churches in Atlanta to examine factors contributing to the willingness to participate in clinical

trials to reduce health disparities. Of the 221 participants, 109 were in the control group, and 112 were in the intervention group. It was found that the intervention group showed a significant increase in intention to seek clinical trials information (p < .05) and intention to join clinical trials (p < .01).

Investigated by Campbell and colleagues (2007), researchers identified health promotion programs including screening, physical activity, and smoking cessation in the faith-based organization of African American churches. Moreover, Powers and colleagues (2019) conducted a study among African American adults in Alabama as a faith-based educational intervention. The study involved using a social-ecological model containing having five levels of influence (individual, interpersonal, institutional, community, and public policy), on health-related behaviors to identify differences in influence before and after the educational initiative. Results showed that participants recorded great improvements in healthy eating practices after the incorporation of the faith-based educational intervention. Lastly, Schoenthaler, Lancaster, and other researchers (2018) conducted a study utilizing the Faith-Based Approaches in the Treatment of HTN (FAITH) in 32 black churches across New York to determine the effectiveness of therapeutic lifestyle changes and motivational interviewing. The therapeutic lifestyle changes

and motivational interview group had significantly lowered SBP compared with the health education group focused on lowering BP among African American people with uncontrolled HTN. The study findings showed that faith-based health interventions were instrumental to the significant lowering of BP in African American people with HTN. From the studies, it is apparent that faith-based health promotion programs conducted in

the African American community result in a reduction in HTN health disparities and improved involvement in research participation.

Many factors have influenced mistrust of medical agencies and their practitioners in African American peoples, contributing to medication non-adherence. The mistrust is particularly detrimental concerning HTN and the importance of adhering consistently to a medication regimen. Given the public health concern of HTN in the African American community, engaging CEnR and faith-based organizations (e.g. churches) to address this public health concern, can bring about more medication adherence.

The PI took a course, 'State of the Science' as part of doctoral training. For the course requirement, the PI conducted an integrative review on 'Health literacy and medication adherence among African American adults with HTN'. The review aimed to identify studies that examined health literacy and medication adherence among African American adults with HTN and report what was known about the relationship between the two variables. Five articles that focused on medication adherence and included a measure of health literacy, all cross-sectional study designs, were located. Only one study aimed to examine the relationship between health literacy and adherence to antihypertensive medications in an all-African American sample. A significant correlation between higher health literacy and higher medication adherence was found in the study. Health literacy was not statistically significant with medication adherence in the remaining studies. Health literacy was reported to be low in the all-African American group. The integrative review revealed that little published literature had specifically focused on the relationship between health literacy and medication adherence in African American population. Based on the findings, the review suggested that HTN health

outcomes in the African American population were suboptimal due to non-adherence to antihypertensive medications, and health literacy might be a key factor to enhance health outcomes hence the need for more research.

#### **Summary**

HTN is a chronic disease that can negatively impact health: African American people are disproportionately affected by HTN (Robbins et al., 2020). Many factors have been associated with the prevalence of HTN including race/ethnicity, unhealthy diet, and sedentary lifestyle. As mentioned earlier, self-care behaviors including a healthy diet, antihypertensive medication adherence, and health literacy have been shown to have a positive influence on BP among people living with HTN. Identified barriers to self-care behaviors are multi-faceted including unemployment, race, beliefs, poor socioeconomic status, poor adherence to antihypertensive medications, and inadequate social support. Individuals globally and especially African American people can achieve good health status by controlling BP through a healthy diet, exercise, health literacy, adherence to BP medications, and adequate social support.

#### **CHAPTER THREE**

#### RESEARCH METHODOLOGY

The methodology chapter describes the process of the research. In narrative analysis, the process includes question development, participant recruitment, data collection, and data analysis. A qualitative research design with the individual narrative interview was used to generate a deeper understanding of lived experiences and told stories of African American adults with HTN (Anderson & Kirkpatrick, 2016; Andrews et al., 2013) and participating in a faith-based health promotion program. The qualitative design utilized a narrative analysis within the paradigm of social constructionism to focus on the lives of individuals as told through their own stories.

## Historical/Philosophical Orientation of Narrative Analysis

Narrative analysis has been used interchangeably with the narrative approach or narrative research to describe the same process: narrative analysis. Narrative analysis is entrenched in different social and humanities disciplines, having ontological and epistemological underpinnings, with scholars and practitioners being discordant on the research process (Daiute & Lightfoot, 2004; Riessman, 2008). Narrative analysis stemmed from literature, history, anthropology, sociology, and education yet the different fields have come up with postmodern organizational orientation (Czarniawska, 2004), psychological (Lieblich et al., 1998), quantitative and qualitative (Elliot, 2005), human developmental (Daiute & Lightfoot, 2004) and sociological (Cortazzi, 2014; Riessman, 2008) approaches (Chase, 2005). Narrative might be the phenomenon being studied or method used in a study, beginning with the experience as expressed in lived and told

stories of individuals (Creswell & Poth, 2018). Narrative analysis is the process of gathering information for storytelling (Creswell & Creswell, 2017), the study of the way human beings have experienced the world, and for a clearer understanding of patients' experiences (Wang & Geale, 2015). Connelly & Clandinin (1990) noted that human beings are storytellers and personally or corporately lead storied lives, and narrative stories are heard and shaped into chronology as individuals talk about their past, present, or future. The narrative approach is unique for generating extremely rich data (Lieblich et al., 1998). Since the terms have been used interchangeably to refer to narrative research, the term 'narrative analysis' has been chosen to explore and better understand the influence of health literacy and social support on medication adherence as expressed in lived and told stories of the African American adults being treated for HTN.

# **Assumptions of Narrative Analysis**

According to Robert & Shenhav (2014), narrative analysis is rich due to its flexibility. The flourishing passion and the rate of developments in narrative analysis over the last few years have contributed to the field's efficacy, adding to the various definitions and assumptions that are fundamental to narrative analysis (Wiles et al, 2011). Therefore, many researchers in social sciences acknowledged the difficulty in having a clear understanding of narrative analysis (Bamberg, 2006; Clandinin & Rosiek, 2007; Czarniawska, 2004; Frost, 2009; Herman, et al., 2007; Riessman, 1993). Narrative analysis "remains a relatively open intellectual space characterized by diversity but also fragmentation" (Stanley & Temple, 2008, p. 276). A study conducted by Robert & Shenhav (2014) produced a typology based on fundamental assumptions underlying narrative analysis present in all studies and are part of their theoretical or epistemological

foundations. The study revealed no strong and stable distinctions in using the terms narrative analysis, narrative approach, or narrative research. The study identified two underlying assumptions in the selected studies premised on two key questions in narrative analysis, namely the *status* of narrative and *perspective* of the narrative.

The status of narrative means focusing on narratives as the very fabric of human existence and seeing narrative as an essential tool that people use to communicate information, identity, and ideas (representational device) (Robert & Shenhay, 2014). Regarding the perspective on narrative, narrative analysis can be seen as an approach or as an object. Narrative as an approach may refer to a paradigm, axiology, or a set of analytical procedures or strategies. The narrative approach is synonymous with a specific paradigm like the interpretive stance in qualitative research. Clandinin and Rosiek (2007) situated narrative as a paradigm having its distinctive ontological roots in John Dewey's theory of experience. Using a narrative approach refers to adopting a set of specific ontological and epistemological assumptions, such as subjectivism, and attention to coconstruction processes of reality. This understanding of narrative analysis speaks to the philosophical grounding of the research more than the methodological procedures undertaken to tackle research material (Robert & Shenhav, 2014). Narrative as an object can be seen as a grand story or conversation, the totality of research material, or an entity found in the research material. Narrative as a conversation or grand story implies understanding some expressions, observations, and positions repeatedly heard in the public sphere in form of themes, debates, and motifs familiar to a group, basically stories about stories (Auerbach, 2009). Narrative as the totality of the research material implies that narrative is the sum of words collected or produced by the research activity in the

form of individual interviews, focus group transcripts, journal entries of participants (Robert & Shenhav, 2014). Narrative as an entity found within the empirical data refers to the existence of a sequence or succession of events (Prince, 2012; Andrews et al., 2013). Hence, an interview, speech, or journal entry could contain multiple narratives. Although narrative analysis is rich in variety, the philosophical underpinnings of narrative status and perspective are helpful to navigate the variety in the field to ensure rigor.

## **Riessman Narrative Analysis**

The study was conducted using Riessman's (1993) narrative analysis to generate a deeper understanding of the lived experience and told stories of African American adults with HTN. In narrative analysis, narrative truths are evolving, contextual, and coconstructed by the researcher and participants (Riessman, 2008). The steps of the Riessman narrative analysis include telling about an experience, transcribing the experience, analyzing the experience, and reading the experience of the participants (Riessman, 1993). Telling about the experience is the presenting of a personal narrative. The participants re-present the events already ordered to some degree, to the researcher in conversations, with all the opportunities and constraints this form of discourse entails. The researcher listens and urges the participants to use probes to expatiate more on the experience. The participants refashion the events in response to the cues and expand on the stories. When participants talk and the researcher listens, the participants and researcher produce a narrative together. The researcher digitally records the story. In transcribing the experience, the researcher represents the story into written speech to transform spoken to linear language (Millett, 1975). Transcribing is an interpretive

practice as the researcher provides a written account and gives meaning to what is said by the participants. In analyzing the experience, the researcher identifies similarities in the story to write a compelling account that increases readers' curiosity (Riessman, 1993). The researcher reorganizes the story into some general framework called 'restorying' (Creswell & Poth, 2018). The researcher creates a metastory about the experience by telling what the narratives signify, editing, and reshaping it (Behar, 2014). Reading the experience necessitates the researcher to prepare a draft of the written report, circulate it to colleagues and participants for reading, and incorporate feedback to the final report (Riessman, 1993).

## **Research Design**

#### Setting

This study used CEnR, a community-partnered approach (Kantamneni et al., 2019; Learned et al., 2017) to engage African American adults with HTN who attended the Live Well by Faith (LWBF) Wellness initiative in Columbia, Missouri. Faith-Based Organizations (FBOs), including churches, are pillars of the African American community, promoting multi-level changes that create healthy and supportive living conditions indispensable to sustaining long-term wellbeing, particularly within underserved communities (Hardison-Moody et al., 2011). Churches are essential in reducing health disparities, and African American churches are used as venues for many programs to reduce disparities between African American people and other racial groups (Campbell et al., 2007). The churches in the LWBF Wellness initiative include Friendship Missionary Baptist Church, Urban Empowerment Ministries, Second Baptist Church, St. Paul AME (African Methodist Episcopal) church, and St Luke United

Methodist Church in Columbia, Missouri. The LWBF is a wellness program in the Black church setting that serves the African American community. The LWBF program was established in 2016 to reduce rates of HTN and diabetes among African American people through identifying the population's unique health needs and promoting healthy lifestyles. Between 160 and 200 people have repeatedly participated in the program. The participants were 95% female and almost 100% of the participants have HTN. The LWBF events include 'A taste of the African Heritage' (cooking course), 'Fit, focused and faithful', Weight Watchers', and 'diabetes coaching'. The program is expanding to include trauma healing (Live Well by Faith, 2019).

#### **Procedure**

The PI formed a relationship with a church-based wellness program, Live Well by Faith (LWBF) in Columbia, Missouri that has a predominantly African American membership. The PI is a doctoral student from the University of Missouri Sinclair School of Nursing in Columbia, MO. The PI had a discussion on HTN among African American adults with the LWBF coordinator. The LWBF program coordinator served as a liaison between the PI and the LWBF participants. The PI developed a working group with the stakeholders: the program coordinator and another LWBF official served as collaborators. The PI, the LWBF program coordinator, and the LWBF official, therefore, formed the research team. The two LWBF officials were responsible for recruiting participants and one of the officials also assisted in scheduling individual interviews.

Two screening questions were used before including participants in this study:

1. Have you been diagnosed with HTN? (answered 'yes')

#### 2. Have you been prescribed medicine for HTN? (answered 'yes')

The PI recognized the inequalities that exist between the academic-community partners and attempted to address these inequalities by developing relationships based on trust and mutual respect, and by creating an empowering process that involved open communication, sharing information, and decision-making power. For instance, in selecting and recruiting participants for the narrative interviews on HTN experiences, the community partners helped to identify the potential participants and determine effective strategies for recruiting them. Forming partnerships and working together with community partners are key to CEnR.

The PI collected data through two main sources: preexisting data and community input. The PI collected data from published literature including epidemiological data on HTN from secondary sources including AHA, CDC, and published research studies on African American adults with HTN. The PI spent time getting to know the LWBF community to establish a relationship to ensure prolonged engagement before approaching the members to participate in the research. The PI attended LWBF meetings aimed at enhancing the health of the African American people. LWBF programs included Walk with Ease and Weight Watchers meetings. The PI gathered information via independent observations during the LWBF meetings. The PI also collected qualitative data through individual narrative interviews on experiences of African American adults with HTN. Each interview participant received a \$25 gift card for their time.

## **Participants Identification and Recruitment**

The study recruited participants from a community of African American adults that were part of the Live Well by Faith (LWBF) initiative and had a diagnosis of HTN. The PI discussed the proposed research study with the LWBF program coordinator, and she gave her consent (see letter of support in Appendix). The PI also attended some of the LWBF events.

**Inclusion criteria:** Adults (age 18 or older) who self-identified as African American, were living with HTN, were on prescribed medications to treat HTN, were part of the LWBF community in Columbia, Missouri, and could speak English participated in the study.

**Exclusion criteria:** Individuals who did not self-identify as African American and individuals who did not have HTN and were not part of the LWBF community were excluded.

Flyers were posted at LWBF participating churches to recruit study participants. The LWBF Program Coordinator, through the churches, informed potential participants attending LWBF events about the study through the recruitment flyer (see Appendix C) and announcements during LWBF events. African American adults living with HTN who were interested in the study informed the LWBF program coordinator. The LWBF program coordinator told the PI, who then contacted potential participants at the LWBF events to provide further information about the study. The PI obtained permission from the program coordinator of the LBWF to conduct recruitment activities and screened the willing participants based on the inclusion criteria.

The PI scheduled individual in-person, telephone, and video (i.e. Zoom) interviews with the volunteer participants. Sixteen people showed interest in the study. The study participants were 15 adults (13 females and two males) who met the inclusion criteria, enrolled in the study, and then completed the informed consent process. The PI conducted one narrative interview with each eligible consented participant. The PI and other research team members were available to answer any questions the participants might have. The interviews were digitally recorded. The PI and professional transcriptionists (TranscribeMe and Temi) transcribed the interviews verbatim. The collected data were stored on a password-protected computer used by the PI. Participants' information was not disclosed outside the research team.

## Sampling/Sample

In qualitative studies, the sample size is determined by reaching a saturation point in the data, when new themes no longer emerge (Mason, 2010), an endpoint known as data saturation. Samples must be large enough to capture all important perceptions, but not so large to the extent that data become redundant and nonessential. According to a study conducted by Guetterman (2015), the sample size for a narrative study in health sciences can range between one and fifty-two participants. Purposeful sampling was used for identification and selection of information-rich cases related to the phenomenon of interest (Palinkas et al., 2015) for in-depth study (Patton, 2014) until the researcher has a clear understanding of the concepts being analyzed in the study and has captured comprehensive stories of the participants, and new information is no longer emerging. Narrative research is best for capturing detailed stories or life experiences of a single individual or the lives of a small number of individuals (Creswell & Poth, 2018).

Purposeful sampling was used to capture detailed stories or life experiences of a sample of 15 participants until data saturation was reached, that is when no new themes were emerging (Faulkner, 2017).

#### **Data Collection Procedures**

Narrative stories occur within specific places or situations and are gathered through many different forms of data like interviews, which are the primary form of data (Creswell & Poth, 2018). Qualitative interviews have been categorized in many ways, including unstructured, semi-structured, and structured (DiCicco-Bloom &Crabtree, 2006). A semi-structured interview allows the interviewer to set the outline for the topics to be covered to obtain reliable and comparable qualitative data (Stuckey, 2013). The interviewer elicits information about the meaning of observed behaviors, interactions, and rituals, with questions emerging over time as the investigator learns about the setting. The PI, therefore, used narrative interviews and field notes to elicit personal narratives to generate a deeper understanding of the lived experience and told stories with regards influence of health literacy and social support on medication adherence among African American adults with HTN. The PI met with each volunteer participant in a mutually agreed upon location. In-person locations included a private room in one of the venues for the LWBF events in Columbia, Missouri, participants' homes, and a regional library. Interviews also took place over the telephone and on Zoom. Each interview session lasted between 17 minutes and 3 hours 13 minutes. Four interviews ranged from 17 - 60 minutes and 11 went over an hour to about three hours.

Qualitative data can be collected in open-ended interviews through three primary approaches, namely informal conversational interviews, standardized open-ended

interviews, and the general interview guide (Patton, 2002). An informal conversational interview entails the spontaneous generation of questions in the natural flow of conversation. Standardized open-ended interview questions are prepared before the interview. Each participant is asked the same question following a particular sequence; a general interview guide is in between the other two approaches and entails the use of an outline of questions ensuring that pertinent topics are covered (Patton, 2002). To help participants create narratives of their experience of living with HTN, a general interview guide was created. The interview questions were based on a literature review on HTN among African American adults, coupled with the researcher's experiences as a nurse educator and a registered nurse in a medical unit. Fundamental questions were developed to elicit information about HTN, health literacy, and medication adherence. Probes were used to elicit details not covered in the initial responses and clarify the antecedents and outcomes of the events described the conditions within which the events took place, and the barriers and enablers of HTN management. Each interview began with the exploratory (open-ended) research question (Saldaña, 2013) "Can you please tell me your story - how did you find out that you have HTN?" The primary question was followed by probes, including "And then what happened?" to seek clarification regarding each participant's experience. After the first three interviews, the general interview guide was revised to generate more detailed participant narratives. The general interview guide contained seven broad questions on the topic of inquiry supplemented by probe questions, including "Can you tell me more about (specific topic)? What was the experience like for you?" (Riessman, 1993, pg.55). Probes were also generated from participants' narratives to encourage in-depth narratives of participants' experiences. The

probes included: "What does having HTN mean to you?". The follow-up questions were based on the emerging themes in the participants' responses during the interview, as answers are given to the question also resulted in evolving conversation (Paget, 1983, p.78). To ensure the interviews captured the lived and told stories of the participants, the interview was concluded by asking each participant, "Is there anything else you would like to share?". The revised general interview guide containing questions and probes was as shown in Table 3.1 (See Appendix G for complete table).

**Table 3.1**General Interview Guide

Guiding Questions	Follow up questions/probes	
Can you please tell me your	In what ways has having HTN affected your	
story - how did you find out that	life?" (social, physical, financial, emotional,	
you have HTN?	physiological?)	
Tell me what you know about	What does having HTN mean to you?	
HTN	What concerns/worries you about HTN?	
Can you please tell me what your BP runs?	Tell me how you check your BP? (how often, where)	
Can you please tell me how you take care of your HTN	What are some of your motivations for wanting to take care of your HTN?	
Tell me what it is like to take	How do you work taking medications into your	
your medications?	daily routine?	
	What do you think helps you with your BP	
	medications as prescribed?	
	What challenges do you face/have you faced	
	taking your BP medications?	

Demographic data were collected through a demographic survey that was administered during the interview (see Appendix F). Demographic data (gender, age, educational level, and insurance status) were collected during the interview. Health data were collected as part of the interview process (that is, behaviors related to medication

taking, medication refills, keeping of medical appointments). After completing the interview and demographic form, each participant received a \$25 gift card for their time and effort. The interviews were digitally recorded, transcribed verbatim, and de-identified (Vandermause, 2011) to develop different types of stories (Creswell & Poth, 2018).

#### The Interview

The PI conducted individual in-depth, face-to-face interviews with the majority (12/15) of the participants; the remainder were conducted via Zoom or phone. The PI conducted the interviews at a site chosen by the participants: the church, regional library, and participants' homes. Choice of location and who decides on the location were important considerations in the power dynamics between the PI and the participants, empowering the participants and making the participants actively participate in the research (Ecker, 2016). The PI conducted one interview over the phone and two interviews over Zoom because of the stay-at-home order due to the Covid-19 pandemic. Each interview was digitally recorded with two recorders. The interviews were conducted until no new themes were emerging (data saturation was reached).

#### **Field Notes**

After the interview, the PI recorded the field notes to ensure undivided attention to allow the PI to reflect on participants' responses to ensure the interview questions were understood in the way the PI intended (McGrath et al., 2019). The data from the field note helped to inform data interpretation.

#### **Ethical considerations**

Ethical issues can arise at several phases, including before conducting the study, at the beginning of the study, during data collection, analysis, reporting, and publishing (Creswell & Poth, 2018). Before conducting the research, ethical approval was obtained from the Health Sciences Institutional Review Board (Health Sciences IRB) at the University of Missouri. When the PI began to conduct the study, each participant went through an informed consent process. While collecting the data, voluntary participation was ensured, and participants were free to withdraw at any stage of the research study. Pseudonyms were used to ensure the confidentiality of the participants. Data were manually coded. The PI de-identified the collected data. To ensure confidentiality, the names of participants were removed from the transcription result. Each participant had a pseudonym; informed consent forms, demographic form, and research data (that is, transcripts, digital recordings, and field notes) were stored separately. The transcripts, demographic form, and list of pseudonyms would be destroyed three years from the date of publishing the final research report. Informed consent forms were stored in a secure box in the PI's office, and the password was known to only the PI.

# **Rigor** (Trustworthiness)

Rigor is the means of exhibiting plausibility, credibility, and integrity of the qualitative research process (Ryan et al., 2007). N. Burns and Grove (2001) asserted that qualitative research critique requires documentation, procedural, and ethical rigor. There was a correlation between the Riessman thematic narrative research guidelines and the

study in question for documentation rigor (Riessman, 2008). For procedural rigor, appropriate data collection techniques incorporating reflexive/critical components were ensured. Pseudonyms were used where needed for ethical rigor and confidentiality (Ryan et al., 2007)

Regarding methodological rigor, credibility was ensured through audit trail, prolonged engagement on the field, and observation of the participants. Peer debriefing was done with two of the PI's colleagues, examining the PI's research methodology, transcripts, and final report. The data were reviewed with a qualitative research expert. Feedback was provided to ensure validity and facilitate credibility. Member checking was done with two participants after thematic narrative analysis for data credibility. The study results were reviewed with the two participants randomly selected to check for accuracy and resonance. For data triangulation, the PI juxtaposed the information from extant literature, observation of the participants, and interview to increase the credibility and validity of the study. Dependability was ensured through an audit trail of transcripts, field notes, and digital recordings. Transferability was ensured through the thick description. Confirmability was ensured through reflexive journals (Tobin & Beglin, 2004; Lincoln & Guba, 1985). Goodness was ensured through explicit explanations of study context, data collection management, and interpretation process.

## **Data Management**

The interviews were digitally recorded and uploaded to a secured computer, transcribed with participants identified by identification (I. D.) codes. Digital media used by the recorder was erased after the upload. The recordings were transcribed verbatim, and each transcription was vetted for accuracy by the researcher by listening to the recording and reading along with the text. Field notes written by the researcher during the data collection were transcribed using Microsoft Word software, and labeled according to date, time, location, and I.D. codes. All transcriptions were saved to a secure file on a

laptop and for easy organization and analysis and saved in a Box account for backup.

Microsoft Word was used to organize the interview data. All secure files and hard copies, including the researcher's field notes, were stored safely in a locked file cabinet that was accessed only by the PI.

## **Data Analysis and Interpretation**

Looking for a set of rules in conducting narrative analysis will result in disappointment due to the narrative analysis being open to new experiences and ideas (Riessman, 2008). As a guide, conducting a thematic narrative analysis will necessitate the researcher first to collect the data (Aronson, 1995). From the transcript, patterns of experiences from direct quotes or paraphrasing common ideas can be listed (Aronson, 1995). The researcher will read the narrative many times (Josselson, 2011). Primary attention will be on 'what' is said instead of 'how,' 'to whom,' or 'for what purposes' (Riessman, 2008). The researcher will work with the transcript, isolate, and order relevant episodes or patterns into a chronological biographical account (Riessman, 2008). The researcher will then zoom in to identify all data relating to the already classified patterns (Aronson, 1995). All statements that fit specific patterns are identified and categorized. Then, related patterns will be combined and cataloged into themes. Emerging patterns are identified when gathering themes. The researcher then builds an argument to support the themes by reading related literature to make inferences from the data. Gathering the theme and studying the literature, the researcher formulates theme statements to develop a storyline (Aronson, 1995).

Riessman narrative analysis (Riessman, 2008) was used to analyze the data and interpret meanings the participants assign to their experiences. Riessman's thematic narrative analysis (Riessman, 2008) was conducted to identify emerging themes and categories. There is no standard set of procedure for doing narrative analysis compared to other forms of qualitative research (Riessman, 1993, pg. 54), but the guidelines followed are as stated below:

- 1. Telling
- 2. Transcribing
- 3. Analyzing
- 4. Reading

Utilizing the guidelines mentioned above, the PI analyzed the data as follows:

1. **Telling.** The PI first collected the data by facilitating context for the research interview based on the PI and the participants' interview schedules. The PI used open-ended questions to encourage narrativization, providing extended accounts of the participants' experience, opening up topic topics, and constructing answers in collaboration with the PI the way the participants found meaningful. The open-ended questions included 'You talked about the everyday stress of work. Can you please tell me more about this? 'When you said when you moved into this place. So, can you tell me what happened at that time?'

Riessman narrative analysis (Riessman, 1993) prefers less structure in interview instruments to provide further control to participants. Therefore, the general

interview guide contained seven broad questions about the topic of inquiry, supplemented by probes like 'what was the experience like for you, the experience of living with HTN?'. The interviews took the form of conversations in which both the PI and the participants developed meaning together. The interview gave considerable freedom to both the PI and the participants. The PI clarified uncertainties with follow-up questions, and the answers informed the evolving conversation (Paget, 1983, p.78). The PI combined the open-ended questions with close-ended questions and the demographic questionnaire.

#### 2. Transcribing

Recording and transcribing are of great importance in narrative analysis.

Transforming talk into written text is a representation and involved selection and reduction (Riessman, 1993). The PI collected the data in the form of interview transcripts and began with a rough transcription, a first draft of the entire interview that got the words and other striking features of the conversation on paper, including crying, sighing, laughing, and very long pauses. The PI then went back to retranscribe the selected portion for detailed analysis. The PI spent considerable time scrutinizing the rough drafts of the transcripts, utilizing analytic induction. The focus for analysis emerged as the PI saw what the participants said. The narrative accounts were jointly produced by the PI and the participants with the underlying paradigm of social constructionism. As the PI scrutinized the transcripts, noting down ideas, themes were emerging stimulated by prior interest as fore structures of interpretation. In transcribing, interpretive categories emerged, and the way the stories were told provided clues about meaning. The PI

listened for the entrance and exit talk to use in transcribing to parse the narratives into numbered lines. However, not all the participants' narratives were bounded (Riessman, 1993). Some of the participants told long stories which the PI did not interrupt except to say 'hm' 'ok'.

#### 3. Analyzing

Riessman (1993) noted that analysis cannot be clearly distinguished from transcription. Close and repeated listening, coupled with methodic transcribing, resulted in insights that shaped how the PI chose to represent the interview narratively. In Riessman's narrative analysis (Riessman, 1993), the PI did not tightly specify the question that will be answered with data from the narrative accounts because analytic induction causes questions to change and new ones to emerge (Riessman, 1993, p.60). For data reduction and interpretation, the PI selected key aspects of longer narratives and retranscribed them. The PI subsequently reduced the narrative segment, excluding the PI's utterances, participants' false starts, breakoffs that may hide the information the PI was interested in eliciting. From the transcripts, patterns of experiences from direct quotes or paraphrasing were listed. The PI read the narrative many times, paying attention to 'what' was said instead of 'how,' 'to whom,' or 'for what purposes.' Excerpts from the interviews were cleaned up of interview conversations as the emphasis in the thematic narrative analysis is on the told, that is the content of the speech (Riessman, 2008, pp 57-58). The PI worked with one interview at a time, isolating and ordering relevant episodes into a chronological biographical account. The PI then zoomed in to identify all data relating to the already

classified patterns and underlying assumptions in each account and coded them.

All statements that fitted specific patterns were identified, paraphrased, and categorized with the corresponding pattern. The related patterns were combined and categorized into themes. Emerging patterns were identified when gathering themes.

## 4. Reading

According to Riessman (1993), an early draft of the work is circulated to colleagues for reading, and their comments are incorporated into the final product. The PI sent the research draft to colleagues who are engaged in qualitative research. The readers' comments were reviewed and incorporated into the final dissertation.

# CHAPTER FOUR RESULTS

This qualitative study aimed to generate a deeper understanding of the lived experience and told stories of African American adults with hypertension (HTN). Narrative analysis was used to better understand African American adults' lived experiences with HTN and to identify similarities and differences across the study participants. This chapter addresses the participants characteristics, data analysis, summary of interview narratives, emergent themes from the interview transcripts, (that is, self-care behaviors, the discovery of the HTN diagnosis, realization that HTN is a chronic health condition with a subtheme 'where do I go from here?', impact of HTN on everyday life, social support with the subtheme 'not always up for grabs') and the study's trustworthiness.

# **Participants Characteristics**

Participants (n=15) in this study were African American adults who had each lived with a diagnosis of HTN for more than 5 years. Participants' ages ranged from 32 to over 70 years (mean age = 59.5). The majority of participants were female (87%); almost half (47%) were retired, and the rest were employed either full-time (40%) or part-time (13%) basis. All participants were high school graduates, and over half (60%) also had a college education. All participants in this study had lived with HTN for at least five years, had primary health care providers and all except one participant had health insurance. See Table 4.1

Table 4.1  $Participants' demographic \ and \ health \ characteristics \ (N=15)$ 

Demographic variable		n (%)
Age	25 – 34	1 (6.7)
	35 - 44	0 (0)
	45 - 54	1 (6.7)
	55 - 64	9 (60)
	65 or older	4 (26.7)
Sex		
	Male	2 (13.3)
	Female	13 (86.7)
Educatio	nal status	
	High school	6 (40)
	Bachelor's degree	6 (40)
	Graduate	3 (20)
Employn	nent status	
	Employed part-time	2 (13.3)
	Employed full time	6 (40)
	Retired	7 (46.7)
Health in	surance status	
	None	1 (6.7)
	Employer	7 (46.7)
	Obamacare	1 (6.7)
	Medicare	5 (33.3)
	Retirement	1 (6.7)
Years sir	nce HTN diagnosis	
	More than 5 years	15 (100)
Availabi	lity of healthcare provider	
	Yes	15 (100)

# **Data Analysis**

The Riesman narrative (Riessman, 1993) thematic analysis was used to examine the interview data (Riessman, 2008). In reviewing the transcripts, the PI looked for statements relating to the experience of living with HTN, specifically concerning medication adherence, health literacy, and social support. Each interview is summarized

and presented in this chapter. The reflection of the PI was also included after each summary based on the PI's grandmother's and former patients' and colleagues' experience with HTN. For each interview question, the PI chose words and phrases that seemed to represent the intent of the statement, words and phrases were coded, and then codes were combined into categories to form themes.

## **Interview Narrative Summary**

Before examining the data across cases, the PI read, re-read, and summarized each study participant's interviews. From each participant's story, patterns were identified: (a) various ways by which each participant discovered the HTN diagnosis; (b) understanding that HTN was a longstanding condition, (c) need to take care of the HTN, (d) need for information on the management of HTN; (e) how HTN had affected their lives, (f) reason for changing diet from high-sodium high-fat to low-sodium low-fat, and from processed and fast foods to homemade, healthy, and fresh foods including fresh fruit and vegetables; and (g) social support from family, church and the Live Well by Faith (LWBF). General descriptions of the participants culled from the interviews are presented below. Names used in this chapter are pseudonyms to ensure confidentiality.

Tasha: Tasha learned she had HTN during an annual physical examination. Some of her family members also grew up to live with HTN. She made lifestyle changes and became a vegetarian. She joined Live Well by Faith (LWBF) and Weight Watchers. Even though she was careful about salt intake, lost about 20 pounds of weight, took medications, and engaged in exercises, her blood pressure (BP) was still high. She thought the HTN was stress-related and had not been able to alleviate stress and did not

care for herself. She stopped taking her medications at one time and her systolic BP was 240 and diastolic BP was more than 100. She sometimes forgot to take her medications and at other times, she could not afford the medications. She kept a pill container and thought having a snack bar may help her to take her medications. She had information about HTN and her motivations for managing her BP included age, family, and wanting to live. She did not want to have cardiovascular complications. She and her family members wanted to get off HTN medications because of possible side effects. She wanted to be healthy and was trying to take care of the body God had given her.

Denay: Denay had lived with HTN for 15 years. She was having migraines, went to her primary care doctor, and discovered her BP was very high. At one time, she stopped taking the medications and ended up being hospitalized for an intense HTN. Her BP had since been stabilized. She experienced dizziness, lightheadedness, and numbness when she had not taken her BP medications. She related stress, obesity, unhealthy eating, and dizziness to HTN. She took care of her BP by taking her BP medications every morning, monitoring what she ingested, cutting down salt and soda intake, taking a lot of water, drinking fruits and vegetables, losing weight, exercising, and listening to her body. Her motivations for wanting to control HTN were a family member and realizing that life was a gift from God. Taking the medications in the morning helped her to participate in and enjoy daily living activities which helped her to continue to adhere to her BP medications as prescribed by her physician. She understood the meaning of HTN, and the information helped to remind her of the importance of taking medications in managing her BP and complications of poorly controlled BP. She stated that continuing in LWBF and personal research made her better understand the information about managing her

BP. She was concerned that the BP medications may just stop working and the right one for her may not be available. Her other concern was her family in case medications stop working for her. In her opinion, she felt the African American community did not like managing HTN by going to the doctor and taking medications. She underscored the importance of knowing one's family health history and paying attention to one's body.

Kessie: Kessie was having a problem with her hand, went to the doctor, was diagnosed with incident stroke, and was placed on BP medications. She had been trying to take her medications to avoid complications. She took her medications daily as prescribed. Her motivation for wanting to control her HTN was being active and being able to care for herself. She reported having no challenge in taking her medications though she sometimes forgot to take them. A pill organizer helped her to set up her medications every week. She understood that eating the wrong food and inadequate exercise could result in HTN and that a good diet, exercise, and adequate rest help to control BP. Her source of information about managing her BP was her healthcare provider. The information helped in taking medications and exercising to keep her BP under control. She reported a good understanding of the information. Her concern about HTN was her inability to use her limbs due to her stroke. She added that she wanted to keep being healthy, being able to take care of herself. She believed God had helped her through the medications, having no stroke again over the years.

**Bonquisha:** Despite a family history of HTN, Bonquisha never experienced symptoms of HTN until she was diagnosed with HTN during her yearly examination. She was more involved in caring for her family and community but going days without any

self-care. She was an accountability partner to people and reported sometimes being out of balance. Her motivation for desiring to control her BP was to feel good and healthy at her cellular level. She preferred not to be dependent on medications. She reiterated the importance of healthy eating, exercise, and drinking water all day to prevent dehydration. She reported confusion about conflicting information from doctors on normal BP readings resulting in differences in BP assessment of LWBF. Her concern was that HTN would stress out organs and was a clue that things were out of balance. She reported checking her BP weekly, trying to live a balanced life, and growing old gracefully. Her busy schedule was a barrier to self-care. Whenever possible, she took care of herself through exercise, and prayer to exercise her faith. Her last BP was maybe 148/74. She discussed issues in the African American community including the prevalence of HTN in the African American community, the stress of being Black in America, convenience foods, high salt intake, medication side effects, people not wanting to exercise or change unhealthy eating, non-affordability of medications and doctors not being culturally responsive. She reiterated the need for self-care especially in the African American community to prevent death from conditions like HTN and attributed true legacy and true success in life to being healthy.

**Daniel**: Daniel was diagnosed with HTN for about 10 years and had a family history of HTN. He discovered he had HTN when he went to the doctor after he stopped exercising and gained some weight. Having high BP made him mindful of people with heart diseases and of staying on his BP medications. A pill organizer and a cup of coffee in the morning served as reminders to take his BP medications. His systolic BP was about

300 at one time and his wife took care of him with herbs, more water, and less sugar. He also took care of his BP by exercising, healthy diet, and his recent BP was about 141/84.

He had information about managing his BP and identified cost being a deterrent to BP management. He related the causes of HTN to stress and anger. He saw stress as a killer and attributed stress to unemployment, low wages, inability to provide for the family, bills, and negative thinking. His panacea for stress included steady income, keeping one's job, paying bills, and being oneself. His major motivation for wanting to take care of his HTN was not wanting to have complications. He would like to know how BP medications work. He thought that healthcare providers could provide information in plain language to enhance understanding. He expressed the need for a health education campaign on African American BP statistics, the action of BP medications, and diet.

He reported that LWBF provided him with information, reminders, and opportunities for exercise, healthy living, healthy eating, gardening, positivity, and weight loss. He liked LWBF being a healthy community opening people up to opportunities, sharing things, and allowing a person to be around like-minded people. He would like LWBF to have a newspaper for sharing information, announcing LWBF events, and involving other churches in LWBF events. He thought the church should provide information about HTN, healthy eating, and support LWBF. He expressed a need for organizations that help the community to reach out through sharing health information through posters, advertisements, and newspapers.

**Shirley:** Shirley was diagnosed with HTN about 40 years ago when having some family issues. She discovered she had HTN when she went to the doctor and had some HTN symptoms. On getting to the doctor, her BP was 238/188 and she was placed on BP

medications. She had a family history of HTN and attributed her high BP to stress related to medical, family, and emotional issues. HTN to her was a silent killer affecting mainly African American people and required attention. She expressed the need to pursue the wellness of one's health and happiness and being one's advocate. Having HTN had affected her sleep pattern negatively and made her mindful of her food intake. She stated that uncontrolled BP would stress the body, and lead to chronic headaches. Even though she did not want medications, she controlled her BP by taking her medications, avoiding some calls that might stress her out, engaging in healthy eating habits, staying calm, and having happy thoughts.

She expressed displeasure at healthcare professionals' attitude towards patients especially to people of color, using people of color as guinea pigs and keeping the people for an unnecessarily long period on a higher number of medications than their White counterparts. She expressed the need to stop racial differences, eradicate the stigma attached to skin color, and for African American doctors to treat African American people with HTN. She felt her current BP medications were not right for her as she experienced side effects of her BP medications. Her last BP was 164/78.

Her motivation for controlling her BP was wanting to break the cycle of HTN in her family. Being educated on BP management helped her take her BP medications. She opined that healthcare practitioners' use of plain language and visual aids will make her better understand information about HTN. Concerning the role of the church in the control of HTN, she would love to help people and educate African American people about HTN. She stated that the LWBF program supplied health information,

demonstrated care, helped her, provided food and opportunity for meeting people, with the coordinator being a motivator and having positive energy.

Keeya: Keeya was diagnosed with HTN in her 40s during a checkup. She was exercising and thought she was gaining weight. She was started on BP medications by the doctor. She was having a lot of stress and taking her medications all the time. She might forget to take her medications in the morning but would take them in the evening. Hypertension was prevalent on both sides of her family. At one time, she got tired of taking her BP and took herself off medications. She later started taking her BP medications again, but her BP stayed up due to stress caused by her family, winter, and Covid-19. She was concerned about antihypertensive medications' efficacy. She was trying to cope with stress by attending church programs, volunteering, and writing.

Having high BP affected her emotionally as she stopped engaging in self-care. She stated that having uncontrolled HTN meant death, and people should not stop taking medications. Her challenge with taking her BP medications was not feeling like taking the medications as she was tired of taking the medications and the side effects. She had a med planner that helped her with forgetting to take medications. She knew that high BP was dangerous, and taking medications, watching weight and salt intake help to control her HTN but she no longer cared too much about her HTN. The information about her BP medications was on the bottle label but a simple explanation would help her to better understand the medication information. She opined that LWBF and family were sources of motivation for wanting to take care of her BP. She reported having taken care of everybody around her but not herself. Even though she sometimes took care of herself by going to a nail salon and not taking alcohol, she was not taking care of herself regarding

stress. Her last BP was 153/87. Her concern about her HTN was not being here for her family. She stated that God's role in managing her HTN was through prayer and the church's role in managing her HTN was having peace, being around God's people, positive people who walk, go to church, take care of their families, provide encouragement, help focus, and by doing positive things. Her family and LWBF also gave her support.

**Chrishama:** Chrishama was diagnosed with HTN about 38 years ago in a routine visit to the doctor and she was placed on BP medications. She related her HTN to a family issue. She did not think that HTN has affected her in any way and stated that her doctor provided her with nutritional information.

She conducted personal research on high BP and discovered that there was no research for people of color and doctors would try different medication combinations to get the right mix of drugs for the people of color. She stated that she did not like being ill and reported headaches as a symptom of her HTN. Her BP was aggravated by pain and ranged from 200/112 to 148/70. At a time, her BP medications were not effective. Eventually, she got BP medications that were effective, but she developed arrhythmia. She realized the need for a healthy diet, exercise, and a positive attitude. She attributed her stress to family and health issues, the white value system, and racism. She handled stress through meditation, social support, and reading magazines. She felt that when she prayed her BP would be lowered. She expressed the need to take care of herself through massage, reflexology, vegetable diet, reducing the frequency of laundry, and pressing clothes. Her challenge with taking BP medications was forgetfulness. Her motivation for wanting to take care of her BP was living a fulfilling life. She took medications because she did not want to feel HTN symptoms, but she

wanted to be medication-free. She liked to control her BP with exercise but needed social support.

She liked the fact that LWBF was easy, and free, with participants consistently walking at their own pace. She opined that LWBF repeatedly created a positive environment, hope, and energy that met people's needs. She acknowledged that the LWBF program was comprehensive, provided information, helped her to know she was not alone and would like to see parenting and taking care of herself be added to LWBF programs. She viewed the church's role in the management of HTN as that of providing support.

Mary: Mary was diagnosed with HTN about 15 years ago when she visited the doctor due to headaches. She was hypotensive for the first half of her life and had a family history of HTN. At a time when she was on BP medications, she misread the medication instructions and thought medications did not work. She later read the instruction correctly, took the medications as prescribed, and started feeling better than before. She then realized she needed medications to live a healthy stable life.

She had information about HTN and believed in managing HTN through a healthy diet and reading food labels. She had her container for medications because forgetting to take her BP medications due to her busy lifestyle was the hardest thing for her. She admitted caring for others but not taking care of herself. She related the cause of her HTN to dietary habits and stress. She stated that LWBF was a support system that provided knowledge, encouragement, positive mindset, an opportunity for walking, healthy cooking, healthy eating, and reinforced her desire to be healthier than before. She attended the LWBF cooking course and learned to use fresh vegetables instead of

canned products and trying different things. She tried to eat a healthy diet though felt that some vegetables were expensive. She would like LWBF to use audiovisuals followed by discussions, and to monitor the sleep, hydration, and weight of participants.

She had information on HTN and took care of her HTN through medications, exercise, and diet - reducing sodium intake, and wanting to use natural spices. The information helped her to make medication taking a priority. She engaged in an exercise in the mornings with a partner but caring for the family was a challenge. She opined that workshops, videos, and scheduled health talks would make people with HTN better understand information about managing BP. Her motivation for wanting to take care of her HTN was living longer, spending time with, and being there for her family. She had been caring for other people but could not visit her doctor as she wanted because health care was expensive. Her concern about her HTN was the risk of having renal disease leading to dialysis. She would like to lose weight and control her BP. Her BP ran between less than 120/70 and 156/120 depending on if she used her BP medications or not.

Joshua: Joshua had a family history of HTN and was diagnosed with HTN about five years ago. He discovered he had HTN when he was having a problem with his hand and went to the doctor during an annual physical examination. He stated that stress led to his HTN and the stress was caused by a high level of empathy associated with his job and talking with his sibling. He took care of his HTN by faithfully taking his medications in the morning, paying attention to his body system, exercise, prayer, music, comedies, achieving balance, and weight loss. The family was important to him and thinking of his

family helped to calm him down. He embraced healthy eating and understood the seriousness of HTN with associated comorbidities, equating HTN with amputation. He advised African American people to pay attention to family genetic patterns. He expressed the need to watch one's diet and properly manage one's BP. He showed concern about young people and the youth violence going on in communities and took classes on healing the racial divide, wanting to be a positive influence on his community.

He had information about HTN and took his medications as prescribed, though affecting his morning routine order. He had a cough as a side effect of his medications at a time and his doctor adjusted his medications. His BP ranged between more than 150/80 and 143/70. His concern about his HTN was the physical effect of headaches caused by the HTN. His motivations for wanting to take care of his BP included wanting to be helpful to people and living a holistic life. He found the LWBF program interesting, providing him support and the opportunity to interact with positive people.

Grace: Grace was diagnosed with HTN at the age of 30. The doctor told her to watch her food intake and lose weight and started her on BP medications. Her doctor tried to find the right medications for her, and she was on Lisinopril for 5 years and unknowingly had a cough as a side effect. She was not taking her medications as prescribed due to her work schedule. Her BP ranged between 128/70 and 150/94 depending on whether she took her medications or not. She took care of her BP through medications, diet, exercise, reducing stress, and social support. She was taking about 36 pills a day and wanted to be off medications. She planned to adjust the timing of her medications with her doctor to ensure compliance. She ate late at night due to her busy lifestyle. She tried to reduce weight through healthy cooking, healthy eating, adequate

hydration, and support of her family and church. Her arthritis limited her level of exercise.

She had a lot of information on HTN from the internet and hospital though keeping information about HTN simple would make it easier for her to understand. She knew that HTN could be caused by anger, driving in a rush, and stress, and could be manifested by dizziness, headaches, and could lead to complications including heart attacks, diabetes, and stroke. She stated that HTN meant to care for herself and live the best life. Her concern about her HTN was being consistent with her BP medications due to the nature of her work. Her motivation to control her BP included wanting to feel good, live long, be healthier, and active. When not taking her medicine, she managed her BP through listening to gospel music, reading the Bible or self-help women's books, being more focused and in a good place. She professed that praying to God gave her inner peace and love to take her medications.

The LWBF had a positive influence on her BP medication usage and her health. After over two decades of struggle, she had noticeable weight loss through the LWBF Weight Watchers program but stopped attending the program due to family issues leading to stress eating. The LWBF's Walking with Ease program encouraged a strong level of commitment towards exercise. She revealed that LWBF saved her life and provided an opportunity for weight loss, prayers, encouragement, positivity, and weekly checkup. Since she joined LWBF 3 years ago, she enjoyed better health and became more active through LWBF community functions. She would like LWBF to have more free activities at other places like gymnasium (for example, the ARC), increase slots in the LWBF programs, continue Weight Watchers half-price, include bike riding programs to get more

people to participate. She wanted everyone to know that LWBF was not just for black people but for everybody to be healthy.

Zahra: Zahra was diagnosed with HTN about 30 years ago and had a family history of HTN. Even though she engaged in increased exercise and reduced sodium intake, her BP was still high, and she was commenced on medications. She had nausea, stomach upset, and dizziness as side effects of her BP medications and was taken off the BP medications at a time. Her BP ranged between 128/70 – 180/95 and her challenges in taking her medications were choking on medications, forgetting to take the medications, and not wanting to take medications. However, incorporating the medications into her routine helped her take her BP medications as prescribed. She engaged in a daily exercise with a family member, healthy eating, hydration, use of flaxseed oil, and BP medications. She engaged in an exercise with her family.

She had information on HTN and being aware of the effects of having HTN warranted the need to take better care of herself including taking her BP medications daily. Family, job, having situations out of control, loud noise, pregnancy, and pretense constituted stress to her. Her concern about her HTN was having to be on medication for life. She engaged in a healthy diet, exercise, weekly BP check, talking to plants, laughter, changing one's lifestyle to a good lifestyle; walking in God's purpose, believing in God's word, and divine instruction helped her to relieve stress. Having someone monitor her use of medication and putting the medications within range of sight would help her with taking her medications. Her motivation for wanting to take care of her BP included wanting to be healthy, and family. She stated that LWBF was her tribe, provided her with social support and self-care. Her church also provided support by encouraging gardening,

relaxation, and divine direction on healthy eating. She would like LWBF to integrate white churches. She opined that audio-visual aids, more classes on HTN management, other people's experiences, and individual effort would help her to know more about HTN.

Natalia: Natalia was diagnosed with HTN during a yearly physical when she was having a medical issue and was commenced on BP medications. Before the diagnosis, she did not have any symptoms of HTN. She knew that HTN was a silent killer affecting body organs and having HTN meant being aware of sodium intake, controlling her eating habits, and changing her method of food preparation. She did not know the daily recommended sodium intake but was trying to keep her BP down.

Her concern about her HTN was having a stroke, heart attack, or losing her limbs as she lost a family member who stopped taking the BP medications for about two years. She checked her BP through a personal BP monitor. Her motivation for wanting to control her BP included a family history of HTN, care for self, healthy living, avoiding stress, and not being controlled by medications. She got HTN information about healthcare professionals and reading the information enhanced understanding. She sometimes forgot to take her medications but having a pillbox helped her to take her medications as prescribed. She did not like taking medications due to side effects as she had a cough with her BP medications but would prefer natural remedies. She expressed the need for exercise and changed her eating habit from processed food to healthy food and her cooking method from frying to baking.

She joined LWBF to lose weight, increase her knowledge on healthy living and eating. The LWBF taught her to live well, exercise, have faith, and engage in healthy

eating including fruits and vegetables. She experienced increased flexibility, adequate hydration, better breathing, and mobility. She would like the Walking with Ease program to be of longer duration in terms of hours. She liked to walk more and preferred to walk with people at the same pace as the walking helped her. She also opined that the church helped in managing BP through burden alleviation, rejuvenation, fellowshipping, and reveling in God's power and love and peace.

Malaika: Malaika was noticed to have elevated BP during a regular physical appointment. She was initially advised to watch her diet and lose weight and not on any BP medication. She was not visiting the doctor regularly as she was not symptomatic and not on medical insurance. She was later diagnosed with HTN by another doctor and commenced on BP medications. Even though the doctor told her to take walks, cut back on calories and lose weight, she was not given adequate information. In her late 30s, she got information from the internet, magazines, and commercials about healthy foods, the need to watch sodium intake, exercising, adequate water intake, and increasing good health points. She expressed the need to attend workshops, turning the information to 3D to make it easier to better understand information about HTN for empowerment.

Having HTN to her meant an individual was not doing the right things and limiting the ability to do God's work as God wanted us to be in good health. Her BP was about 140/80. She knew that not taking BP medications regularly could trigger HTN resulting in physical limitation, heart attack, stroke, feeling like a failure, and death. As such, a person with HTN would need to exercise regularly, engage in healthy eating, and adequate hydration for proper body function. She took care of her HTN with BP medications, healthy eating, exercise, and prayer. Her challenge in taking her medications

was forgetfulness. Her concern about her HTN was her heart rate being out of control and the side effects of the medications. Even though she stopped taking her medications at a time because of disbelief in the potency of the medications and non-affordability of the cost of the medications, her motivation for wanting to take care of her BP included her work, need to live, not wanting her heart to stop, and helping others.

From her viewpoint, the disparity was created in the African American community due to lack of information, and substances like high fructose corn syrup, cigarettes, and liquor were introduced to kill people of color. She stated that LWBF helped to increase awareness of HTN, identify and acknowledge the prevalence of HBP, provide an avenue to communicate with other people with similar experiences, and proffer practical solutions to control and manage HTN. She joined LWBF as she was excited to find a specifically designed program for African American people, to acknowledge God, share experiences, recipes, struggles and fellowship together. The program also provided her the opportunity to focus on healthy eating, discipleship, and empowerment. She would like LWBF to develop health ministry in home churches. She would like to have an affordable weekly massage to take care of her HTN. She stated that accountability partners would be of great benefit and wanted people to be accountable for others not minding their feeling, to encourage others, and ensure healthy eating and healthy living. In her opinion, the role of the church in the management of HTN was to support the body, honor God and maintain the spiritual and physical temples through prayer, and bible study.

**Kendy:** Kendy was detected to have HTN during a health fair, later confirmed by her doctor about 20 years ago, and placed on antihypertensive medications. She had a

family history of HTN. She kept track of her BP and started exercising and incorporating fruits and smoothies into her diet. Having HTN created the need to remember taking her medications or she would have headaches and her BP would be high. She stated that she listened to a program and was told that people with underlying health conditions and HTN were more susceptible to the corona virus. She had varying SBP of 120-135 and experienced tiredness as a side effect of her BP medication though she did not think she had any side effects of her medication. Her concern about her HTN was being healthy. She tried to lose weight by eating fruits, making smoothies, and being on a weight loss diet. She expressed the need for a medication reminder. Aside from taking care of her HTN through the use of BP medications, healthy eating, and exercise, she expressed the need for regular use of medication, exercise, and weight loss. Her motivation for wanting to take care of her BP included being around for her family.

She got information about her HTN from watching TV, health books, and her doctor. Although she was given information every month and knowing that reading the information would make her to better understand the information given to her about managing her BP, she was not reading the information. Her motivation for staying healthy was her family. She thought regular exercise and a healthy diet would help in controlling her BP. She asked the PI for more information about HTN, the effect of caffeine and tea on HTN.

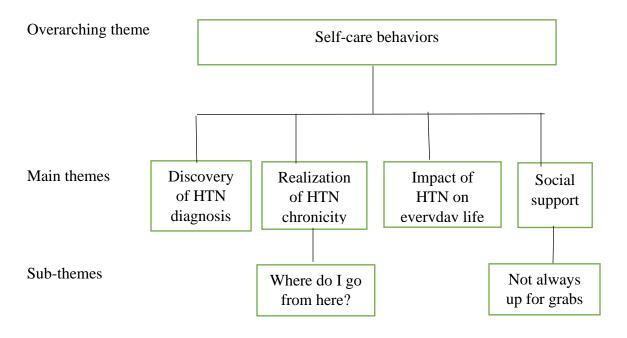
Kendy joined LWBF due to her interest in improving overall health. The LWBF provided her with knowledge of healthy eating, cooking, sharing information, recipes, interaction with different people, served as a reminder of the health disparity, and to live well by faith, though she had difficulty attending the program due to job and family

issues. She liked the LWBF meetings, listening to the health talks, and participating in the exercise program as she planned to exercise, lose weight, and lower her BP.

The PI generated themes from the participants' narratives. The PI read the narratives several times and arranged relevant data into biographical accounts. After reading through the cases, cross-case analysis was done to identify related patterns. The related patterns were combined and categorized into themes. The themes are depicted in Figure 4.1 below:

Figure 4.1

Themes identified from participants' experiences



Note: Themes were generated from the experiences of the participants living with HTN.

## **Narrative Themes**

From the data analysis, one overarching theme emerged: self-care behaviors in HTN. Four main themes emerged from data analysis: (a) discovery of the HTN diagnosis, (b) realization of HTN chronicity, (c) impact of HTN on everyday life, and (d) social support. Two sub-themes were identified from the main themes: (a) where do I go from here? and (b) social support: not always up for grabs. The themes and exemplar quotes are as depicted in Table 4.2 below:

Table 4.2

Themes and Exemplar Quotes

Overarching theme		Exemplar Quotes
Self-care behaviors		"I'm taking this medication I'm eating vegetables I listen to my musicI do a few little exercises on the bedand listen to the instrumental music the candles, I like my candles that bring your BP down." (Shirley, female, age 67).
Main themes	Subthemes	
Discovery of the HTN diagnosis		"When I was 29, I was pregnant with my second child. And um, I went in for physical and found out that I had high BP. Um I'd not had it before.". (Tasha, female, age 64).
Realization that HTN is a chronic health condition	Where do I go from here?	"I've been having a lot of stress. My BP shot up."  (Keeya, female, age 67)  "Having high BP means that you are at risk for, uh, (clear throat) for an episode like uh, heart failure, heart attack um, yeah, really you know to me it's all or nothing." (Daniel, male, age 63).
Impact of HTN on everyday life		"I take high BP medicine once a day in the morning and I do it every day so as far as that goes." (Joshua, male, age 55-64)
Social support	Not always up for grabs	"So, um, there are some kitchens in our churches that have signs that say 'no fried foods' but you know what they'll do now, go get the fried chicken from the chicken place and bring it in." (Bonquisha, female in her 60s)

Overarching Theme: Self-care behaviors in HTN

All study participants discussed self-care behaviors in the management of HTN. Self-care behaviors of the participants included the use of antihypertensive medications and lifestyle changes including a low-sodium diet, exercise, smoking cessation, and social support. Mary said:

Oh, I take care of my high BP by taking my medication and trying to limit my sodium intake. When I can, and trying to drink more water when I can drink by myself (Mary, female, 70)

This statement conveys that Mary and other African American adults were engaging in self-care behaviors in the management of their HTN. It is pertinent to take antihypertensive medications, eat a healthy diet and engage in exercise to control BP. Some of the participants also talked about changing methods of food preparation from frying to baking and from eating convenience foods to homemade foods to ensure a healthy diet. Participants also engaged in self-care behaviors due to family history of HTN, wanting to help other people, family, nature of work, and wanting to live long.

However, in taking care of themselves, the participants spoke about barriers to the management of the HTN including the attitude of healthcare professionals, and stress. They reported that healthcare professionals did not like being questioned by people of color and that healthcare providers were not finding the right combination of antihypertensive medications for people of color. The participants also reported stress (financial, physical, and emotional stress) as a barrier to engaging in self-care to manage their HTN.

Even though some participants reported engaging in exercise, some of the participants admitted inability to engage in exercise due to taking care of their families. The participants also discussed challenges to medication adherence including busy schedule, forgetfulness, and cost of medications.—The self-care behaviors are reflected in the following four main themes and two sub-themes.

#### Main Theme 1: Discovery of the HTN diagnosis

To engage in self-care behaviors, there is a need to discover the health issue. The study participants had different ways of discovering the diagnosis of HTN. Many of the participants discovered having HTN through routine medical checks, few participants during pregnancy, two participants during stressful life situations, one participant discovered at a health fair later confirmed by the doctor, and few had symptoms. One of the participants spoke about the discovery of her HTN through routine medical check:

'I found out when I was about 30 years old when I was pregnant.... So, then when they got my BP, it was like skyrocket...' (Grace, female, 60)

The discovery of the HTN diagnosis made the study participants be aware of HTN and thus the need to cope with the illness. Being able to cope with illness is part of self-care.

#### Main Theme 2: Realization of HTN chronicity

All the participants had been living with HTN for a long time, for at least five years and as long as over 40 years, showing that HTN is a chronic health condition. After the discovery of the HTN, the participants realized that HTN was a chronic condition that can be caused by different factors and needed to be managed through different means.

Causes of HTN as relayed by the participants included family history, stressful life

situations, unhealthy eating including eating late, stress eating, family tradition - eating salty food, eating unhealthy food, stoppage of exercise, and weight gain. One of the participants spoke about the cause of HTN:

'Yes. My mother has it (high BP) my father had it'. (Daniel, male, 63).

Two of the participants also attributed stressful situations to HTN. One of the two said,

'So, do I have high BP? Cause I was in a bad marriage' (Chrishama, female, 72).

The chronicity of HTN made the study participants realize the need to engage in self-care behaviors.

*Sub-theme:* where do I go from here?

Upon the discovery of the HTN diagnosis and realization of chronicity of HTN, the participants discovered that living with HTN is a journey that necessitated getting information. The participants reported obtaining information about HTN from different sources including the internet, media, and health care providers. The information included causes of HTN, what happened in the body when someone had HTN, complications of HTN, and the need for management of the HTN. Management of HTN warranted the need for healthy food preparation and eating, exercise, adequate sleep, antihypertensive medication adherence, adequate water intake, and social support. When asked about the meaning of HTN, most of the participants affirmed that HTN meant being at risk for complications, need to watch food intake, change in dietary habits, engaging in exercise.

'I know it can lead to heart disease and strokes' (Mary, female, 70)

This statement reveals that Mary and other study participants recognized the complications of HTN. The diagnosis of HTN made the study participants seek information needed to make health decisions (health literacy) about their HTN. Wanting to know more about HTN is part of self-care behaviors in HTN management (Yatim et al., 2019).

#### Main Theme 3: Impact of HTN on everyday life

For the participants, the realization of HTN chronicity resulted in the management of HTN including daily lifestyle modification. The participants managed the HTN by monitoring BP, taking medications, healthy cooking, healthy eating, exercise, sleep, and stress management. Taking medications warranted the incorporation of medication use into the daily routine. Specific facilitators of medication adherence included reminders/alarms, putting medications in the kitchen, having a snack beside the HTN medications, having an accountability partner, and pillboxes/organizers. An accountability partner is someone who holds the other person accountable to help keep their commitment in terms of engaging in self-care behaviors like taking medications as prescribed, engaging in exercise, and healthy food preparation and eating. Even though one participant agreed that having an accountability partner was good, she did not agree to have one due to not wanting to be a burden to another person. Healthy cooking necessitated the change of cooking method from frying to baking and using less or no salt in cooking. Healthy eating resulted in the change of diet; eating homemade food as opposed to processed food; reducing intake of fast foods; eating fruits and vegetables; adequate hydration; and watching sodium content of canned foods. Some of the participants engaged in exercises with families or friends and trying to have adequate sleep. Specific facilitators of engaging in exercises included affordable /sliding

scale cost of the gymnasium, having an exercise coach to train an individual how to exercise and use gym equipment, and accountability partners to help ensure constant engagement in exercise. A favorable (warm) weather is also a facilitator of exercise. One of the participants also spoke about different ways of handling stress:

"...I do the Zumba dance. Um, happy thoughts, remove myself from stress...when my phone ring, I know the person on the other end is going to have me to have a bad day or just stress me to blank out. I don't pick up my phone' (Shirley, female, 67).

This statement shows that Shirley and other participants managed their stress in addition to dietary change and antihypertensive medication use. The participants also mentioned facilitators of HTN management. This included family, God, work, a strong desire to be healthy, avoid complications, live long and feel good, break the cycle of HTN in their family, medicinal independence, and helping other people.

However, the participants revealed some challenges they experienced with managing HTN. The challenges included forgetting to take medications, busy schedule, lack of self-care, societal racism, Covid-19, unfavorable weather (winter), health care professionals' attitude to people of color resulting in lack of trust in the healthcare system, and non-affordability and side effects of medications:

'Why would you take medicine that might do somebody the- has a side effect you might have from brain, um, function or something different from. I do not want, I don't want to take medicine like this stuff it be okay on one thing, but if it's going to mess your inner body up and stuff, I don't want it' (Natalia, female, 55-64).

#### Another participant stated:

'I started getting the headaches again... I called the doctor "Oh you're fine you just need to rest"...her nurse said ... "well the doctor, she's not worried she doesn't care about how high your top number is" they're using us, it's a trial and error. I

feel like a guinea pig.... it's no reason why I should be on three different medications BP medications to, to combat my HTN when people, not my color are on maybe one pill to take. I have a problem with that'(Shirley, female, 67).

One participant talked about eating:

'Eating in a vegetarian manner is very rewarding and it costs more (Chrishama, female in her 70s)

From the participants' responses, living with HTN has an impact on daily life.

There were barriers to engaging in the use of medications, exercise, and healthy eating which are all part of self-care. Even though the participants knew that medications and a healthy lifestyle could help with BP control, the barriers prevented the people from engaging in self-care.

#### Main Theme 4: Social support

With the impact of HTN on the everyday life of the participants, there was a need for social support which included emotional support, informational support, instrumental support, and appraisal support. The majority of the participants received social support from family, spiritual sources, and Live Well by Faith (LWBF). The family included spouses, children, nephews, and grandchildren. Spiritual sources were God and the church. The LWBF included the coordinator, speakers, and members. The LWBF speakers talked about the importance of healthy eating, exercise, use of medications, and adequate water intake.

Emotional support received from family members and LWBF included caring, providing listening ears, having trust in, motivation, sharing experiences of living with HTN, and socialization with other members of LWBF, knowing one is not alone, and peace from God. Instrumental support from LWBF included ensuring that every LWBF

member had a primary care provider and giving participants ingredients to prepare healthy meals for their families after the African Heritage cooking session. The LWBF also organized a 'Walk with Ease' program where participants engaged in exercise for 30 minutes three times a week for six weeks. Instrumental support from family members included offering to work out at the gymnasium with one of the participants, provision of cooking course and resources by LWBF, and provision of land for gardening by the church. Gardening provided fresh fruits and vegetables. Family members volunteering to work out with the participants helped to encourage participation in exercise. Informational support included advice and information from family members, church, and LWBF regarding engaging in exercise, healthy eating, healthy cooking, adequate hydration, and sharing of useful resources. Appraisal support included information that was useful for self-evaluation in form of monitoring of BP and weight by LWBF and monitoring of food intake by family members. Monitoring of BP helped to know if the BP was controlled or if there was a need for referral to the doctor for further management. One of the participants relayed support received from family:

'my son? Well, he'll be first to call me (out) if he sees me eating something I shouldn't be eating. If he goes fix my plate he fixes in servings because a lot of times I might not watch it because you know even if you're eating good food if you're eating too much it's still not good. He doesn't get too much of that on their plate' but he'll say, 'let me go fix your plate' (Grace, female, 60)

The participants highlighted the roles of LWBF in the management of their HTN. One of the participants spoke about the support received from LWBF:

'Live Well by Faith. That really motivated me a lot of stuff. If you want me to tell you the truth, that program helped save me...it encouraged me, motivate me a lot...if I hadn't been going to that program ...I don't know what would have happened (pause...) having people come there to tell you about your exercise,

your health, your medication, they weigh you, .. take your BP... talk to you... exercising, eating right, ... socializing, teach you how to bend, teach you how to cook... getting up, doing things for myself... eating food...drinking water (Keeya, 67, female)

Many of the participants reported having social support through families and the LWBF which helped to facilitate self-care (Jo et al., 2020).

Subtheme: Social support- not always up for grabs

In contrast, few of the participants reported not receiving support from church or families. Even though the church was trying to be supportive and talked about healthy eating, the church still served fast foods including fried chicken during church events.

Some participants opined that family members did not support healthy eating or engaging in exercise. One of the participants said:

'I have a mom and a husband who aren't on my team they don't want to eat the way I desire to eat and it's very hard' (Bonquisha, a female in her 60s).

Taking care of family members also constituted stress for some participants. The concerned participants reported taking care of family members and even the community but did not take care of themselves. To the participants, the family served as stressors instead of providing social support. One of the participants had this to say:

'my family. They get on my beep beep nerves. It's like the Mardiyah family reunion, oh, oh. But seriously um, just putting myself in a happy place. There's just too much stress going on, too many issues. You know life happens, family and you try to help but. It's just what I'm saying, your family is the main ones that can bring you down, and just living with that every day is very challenging you know, trying to be the big person with a listening ear and they're venting and all that after a while has a toll on you. It's very draining, it's time-consuming and it's very draining' (Shirley, female, 67).

This statement shows that even though beneficial to self-care, social support was not always available from families. Apart from Shirley, some participants also reported that family members did not have the same pace as them when walking. Differences in pace discouraged the participants from exercising with family members.

#### **CHAPTER FIVE**

#### **DISCUSSION/CONCLUSIONS**

The purpose of this study was to generate a deeper understanding of the lived experience and told stories of African American adults with HTN participating in a faithbased program in the Midwest. Several studies have been conducted on HTN among African American people (Butler et al., 2017; Covassin, et al., 2018; Forde et al., 2020). However, few studies have explored the experiences of African American adults living with HTN and participating in a faith-based wellness program. Therefore, to understand the experience of African American adults living with HTN and participating in a wellness intervention, this study sought to answer this research question: What is the experience of living with HTN for African American adults participating in a faith-based wellness program in mid-Missouri? One overarching theme, Self-care behaviors in HTN, four main themes, Discovery of HTN diagnosis, Realization of HTN chronicity, Impact of HTN on everyday life, Social support, and two subthemes, Where do I go from hererevealing the uncertain journey of living with HTN (from the main theme: realization of HTN chronicity) and Social support; not always up for grabs were key findings that emerged upon analysis of the African American adults' narratives. This chapter contains the meaning of the study findings in comparison with extant literature, the significance of the study, the limitations of the study, implication of study findings for practice, education, future research and policy, and conclusion.

#### **Discussion**

Findings from this study provide a salient understanding of reasons why participants felt that their BP readings were not controlled (that is, within the normal range of 2017 AHA guidelines). The use of Riessman's thematic narrative analysis (Riessman, 2008) in this study to uncover new experiences of living with HTN among African American people that participated in the LWBF is novel. This is the first study conducted on HTN among the LWBF participants using Riessman thematic narrative analysis. By focusing on the population, new insight into barriers and facilitators of HTN management was gained.

The themes that emerged from this narrative analysis were in tandem with previous literature (*Self-care behaviors in HTN* - Ademe et al., 2019; Niriayo et al., 2019; Ea et al., 2018; *Discovery of HTN diagnosis* - Akpore et al, 2016; Brown, Magee, et al., 2018, Garrison & Oberhelman, 2013; Nguyen, Wright, et al., 2016; Sutton et al., 2018; *Realization of HTN chronicity* - Bazargan, Smith & King, 2018; *Impact of HTN on everyday life*- Armstrong et al., 2019; Schmieder, et al., 2017; *Social support* - Asgari et al., 2019; Turan et al., 2019). All the participants revealed different ways of discovering the HTN diagnosis through the told stories. Particularly, the discovery was through routine medical checks, prenatal care, health fair, and the manifestation of HTN symptoms. (Early) Diagnosis through routine medical checks, prenatal care, and health fair is essential for assessment, discovery, and management of HTN, and reduction of cardiovascular-related complications (Akpore et al., 2016; Berger & Beghetti, 2019; Brown, Magee, et al., 2018; Kario, & Wang, 2018; Nguyen, Wright, et al., 2016; Schwartz & McManus, 2015).

The use of annual physical in hypertension screening is not well documented in the literature (Xu et al., 2020; Zhang et al, 2017). In this study, most African American adults did not have any symptoms of HTN until they checked their BP during the annual physical examination. The HTN treatment began after the diagnosis. This finding indicates that HTN can be a 'silent killer', African American people might not know their BP was high and may die of heart-related complications including myocardial infarction. An autopsy may be the only means by which the cause of death will be known and by then, it will be too late for any medical intervention resulting in 'medicine after death'.

The participants also relayed the causes of HTN as family history, stressful situations, busy schedules, and unhealthy lifestyle. Evidence such as 'it's good to know your family history...being diagnosed at 17 with hypertension. I never knew until I was in my mid-20s. Then my father, both his little sisters all have hypertension' corroborates previous studies that reported family prevalence of HTN (Mounica et al., 2020), busy schedules (Carter-Edwards et al., 2018), and unhealthy lifestyle (Adinkrah et al., 2020) among African American people.

The realization of chronicity of HTN was evident as the participants had been diagnosed for at least five years, and as long as over 40 years, having an impact on the everyday life of the participants. The diagnosis necessitated control of the HTN including integrating the use of medications as prescribed in their daily schedule, dietary changes, engaging in exercise, and social support through family, God, church, and the LWBF. This implies that African American people addressing HTN in their community is pertinent and includes daily commitment, consistency, and discipline. Extant literature highlights the importance of a healthy diet, use of antihypertensive medications, exercise,

smoking cessation, reduction of alcohol in control of HTN (Alsinani, et al., 2018; Niriayo et al, 2019; Sharman et al., 2019). Richards et al. (2019) examination of African American people's attitude towards healthy eating discovered that participants consumed a large number of empty calories and a smaller number of whole foods and total protein food. Identified barriers to healthy eating included cost and absence of fruits and vegetables at home. Therefore, the lack of consistency in engaging in lifestyle modifications expressed by the African American participants in this current study might be due to the cost of healthy food.

The study participants' responses to the impact of HTN on everyday life revealed some barriers to effective BP control including barriers to medication adherence and health literacy. Specific barriers to HTN medication adherence included forgetfulness, cost of medications, disbelief in the potency of medications, medication side effects, medications not working, polypharmacy, stressful situations, busy lifestyle, not wanting to take the medications (Najimi et al., 2018), and lack of social support, all which have been well documented (Mayo-Gamble, & Mouton, 2018; Nguyen, Schuiling-Veninga, et al., 2017; Ruppar et al., 2017; Brown, Bussell, et al., 2016). One participant reported not taking antihypertensive medications due to 'no reason at all'. Other barriers to BP control identified by the study included stress, cost of the gymnasium, family, worry about the diagnosis, and healthcare professionals' attitude to people of color. Literature shows that the historical and current attitude of healthcare professionals to people of color led to distrust (Jaiswal, 2019; Powell et al., 2019). The healthcare professionals' attitude might serve as a deterrent to medication adherence in this population. If an individual feels being treated differently from other people in a negative manner regarding their health,

the individual may not trust the care or clinical judgment of the health care provider and may not adhere to the regimen of care prescribed. The dissatisfaction expressed by the participants may be rooted in historical discrimination and lack of cultural sensitivity/humility among healthcare professionals towards people of color, which engendered the African American people to call for assistance from African American healthcare professionals. Regarding health literacy, even though the participants reported obtaining information from health care providers, family members, and the internet, specific barriers to health literacy included inadequate information about HTN, reading information wrongly, unclear health information, and medical verbosity. Evidence such as 'I think maybe they should make it not so, uh, so hard to read, you know when you get your BP medicine from the doctor, it's got 100 different things on there, just make it plain.. for people to understand' demonstrate that unclear and medical verbosity can hinder persistent use of medicine. The medical verbosity might make the provided information difficult to understand and mitigate health literacy leading to antihypertensive medications' nonadherence.

Even though some participants reported enjoying social support from family and LWBF, it is noteworthy that social support was not always available based on the findings of this study. Social support plays a key role in health literacy and medication adherence essential for BP control (Atukunda et al., 2017; Mayo-Gamble, & Mouton, 2018). However, some participants' responses showed that instead of serving as support, the family served as a stressor, mitigated participant's engagement in healthy eating and exercise, and taking care of families did not allow the participants to take care of themselves. This contrasts with many studies on social support in HTN management

(Asgari et al., 2019; Turan et al., 2019) which opined that family is a source of social support that improves adherence to HTN management. If the family could not provide social support, this is a big issue in the African American population that underscores the importance of family in providing care in chronic disease management.

Even though the church was supposed to be at the forefront of health care, providing multi-level care, this study found that there was inadequate support from the church. Some participants reported that the church provided support through health ministries and providing land for gardening. Church in African American settings has been known to promote the health and wellness of individuals (Johnson-Lawrence et al., 2019). However, there was inadequate support due to church leadership issues and serving fried food at church functions. Fried foods are unhealthy and can contribute to a high level of cholesterol in the body with cardiovascular mortality (Sun, 2019).

In addition, many of the participants wanted to be off medications. HTN is a chronic condition that necessitates taking antihypertensive medications for a long period to ensure BP control. The participants reported side effects of the medications including gout, arrhythmia, facial and lip swelling, cough, and tiredness, Healthy eating, exercising, adequate sleep, and stress management will go a long way in control of BP which may ultimately lead to being taken off antihypertensive medications.

# **Strengths and Limitations**

This study is novel in utilizing Riessman's thematic narrative analysis (Riessman, 2008) to uncover the journey of living with HTN among African American adults participating in a faith-based wellness program. The methodology allowed the

participants to tell their individual story, and for the PI to understand the interdependency between various social factors and the changes that underlie the complexity of the HTN journey. The methodology also allowed for restorying to create a metastory. The narratives framed the experience of living with HTN in the context of the perspective of African American adults participating in LWBF. While some of the study findings agreed with existing data, new themes were uncovered through the participant narratives. These included the importance of social support: "not always up for grabs", that is, social support was not always available.

This study has limitations that should be taken into consideration when interpreting the findings. An inherent limitation of this study is the response bias of the self-reported experience. Each narrative of the participant is dependent on the context of the teller of the story and the researcher who analyzes and interprets the story. To partially overcome the limitation, post-analysis random member checking was done to increase the internal validity of the study. Each study participant may also have the narratives contain talks and texts that may either partly, selectively, or imperfectly represent part of the story. Participants may also not remember details and therefore did not share the details during the interview. In addition, purposeful sampling led to a homogenous sample of educated, health insured, and mostly employed people. Even though the participants tried to overcome barriers to the management of HTN, they underscored the importance of consistency of self-care behaviors in HTN management. In as much as these data add impactful knowledge to HTN management, it is a qualitative study within one specific community and hence, findings are not generalizable to other vulnerable minority groups, such as Hispanic adults with HTN. Nonetheless, these data

provide an in-depth description of participants' experiences and contribute valuable knowledge of the African American community. The data are important given the disproportionate burden of HTN among African American adults compared with other racial groups in the United States.

### **Implications**

This study contributes to the body of knowledge and paves way for implications in the areas of future research, practice, and policy. The suggestions may help enhance research among the underserved African American people. The implications may also help to facilitate patient care and support wellness organizations to improve the health status of African American people with HTN.

### **Implications for Future Research**

More research is warranted around support from family and church regarding engagement in adherence to lifestyle behaviors that enhance HTN health outcomes. For example, BP checks, exercise, and dietary changes aid in controlling BP. Health disparities in HTN outcomes still exist, despite available effective interventions (Ferdinand et al., 2017). Future studies may explore early HTN discovery and management in African American people in teenagers, stress management among African American adults with HTN, and HTN management among Hispanic adults. Notably, the present study was conducted among African American adults who participated in a faith-based wellness program. Future studies may design an intervention providing accountability partners for each African American participant to see if there will be an improvement in the management of HTN. The need for self-care was disclosed

consistently by most of the participants. They reported having busy lives and having to take care of the people around them, yet not caring for themselves. Care of the family need not be one-sided: family members need to care for one another so that every family member may enjoy care. It is pertinent to identify ways of taking care of self among African American people. This includes being proactive and carving out time for self-care including exercise and healthy eating and adjusting work schedules allowing routine use of medications is of paramount importance. Self-care and time management programs may be organized so individuals and their families can learn how to carve out time for their self-care. Future research may also focus on support from the church including monitoring of congregants' BP by health ministries during church events, early discovery HTN referrals, and adherence to therapeutic lifestyle change interventions.

## **Implications for Practice**

Many participants reported the discovery of their HTN diagnosis during routine medical check, prenatal care, or health fair event. The HTN asymptomatic nature may be responsible for unintentional medication nonadherence among the participants and health disparity in the African American population. African American people need to check BP earlier in their lives for early detection and management of HTN. This will help to forestall complications including heart failure and myocardial infarction resulting from prolonged, untreated HTN. Nurse-led intervention programs including consistent monitoring of BP and nutritional guides for healthy eating may also be helpful in BP control. Healthcare professionals need to provide HTN screening and HTN awareness programs for African American people. Healthcare professionals also need to provide clear, simple information on a healthy diet and medication using easily understandable

language that patients will understand. Healthcare professionals need to embrace cultural humility/responsiveness for self-awareness of personal biases and self-reflection, challenge power imbalances, and affiliate with advocacy groups to foster trust and patient-centered care.

### **Implications for policy**

The LWBF provided social support and was a positive experience to all the participants in this study. Policy for the establishment and maintenance of public health initiatives like LWBF is highly advocated for. Due to the worldwide prevalence of HTN, public health initiatives utilizing culturally, and religiously tailored interventions should be promulgated across the globe. Critically, government policy is needed to support health initiatives like LWBF to provide the needed informational, emotional, instrumental, and appraisal support to help individuals manage their HTN. The public health initiatives may post fliers via social media or create websites to disseminate information about the organizations' activities. The information will create awareness of the wellness initiatives and may increase the number of people participating in the wellness program thus reducing morbidity rates of HTN.

#### **Conclusions**

This narrative analysis provides an insight into the experiences of African American adults with HTN participating in a faith-based wellness initiative. The overarching theme, 'Self-care behaviors in hypertension management' relayed the activities the participants engage in to control their BP. The main themes and subthemes illuminated the activities. Throughout the data collection, each study participant shared

meaningful and personal stories about the diagnosis of HTN, discussing what led to the diagnosis. Diagnosis discovery resulted in realizing that HTN was a long-standing condition and had an implication on everyday life. The chronic nature of hypertension necessitates consistency in healthy eating, antihypertensive medication use, and engagement in exercise which may be facilitated by social support and health literacy. Finally, some challenges were encountered including the non-availability of social support which served as a roadblock to lifestyle modifications. Future research should look into interventions that enhance health literacy and social support from the healthcare system, family members, and church among African American people living with hypertension.

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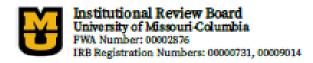
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#### **APPENDIX**

#### Appendix A: Institutional Review Board Approval Letter



482 McReynolds Hall Columbia, MO 65211 573-882-3181 irb@missouri.edu

April 20, 2020

Principal Investigator: Christiana Oluseun Oyewusi

Department: Campus Dining Services

Your Amendment Form v.2 to project entitled The experience of living with hypertension: African American adults participating in a faith-based wellness program was reviewed and approved by the MU Institutional Review Board according to the terms and conditions described below:

IRB Project 2019210 Number

IRB Review

263378

Number

Initial

Date

Application January 31, 2020

Approval Date

Approval Date April 17, 2020

IRB Expiration

January 31, 2021

Expedited Level of Review

Application.

Approved Status

Project Status Active - Open to Enrollment

Risk Level Minimal Risk

Written Consent Type of Consent

Consent with Waiver of Documentation

HIPAA Category No HIPAA

IRB Approved Consent Document - Zoom and phone interviews

Oyewusi social behavioral educational protocol 04152020 clear copy shows Approved.

modification in the previous protocol in the areas of date, version form consent, Documents

study procedures (conduct and recording of interview) and compensation not

highlighted

The principal investigator (PI) is responsible for all aspects and conduct of this study. The PI must comply with the following conditions of the approval:

1. Enrollment and study related procedures must remain in compliance with the University of Missouri regulations related to interaction with human participants following guidance at https://research.missourl.edu/about/covid-19-info.php

- No subjects may be involved in any study procedure prior to the IRB approval date or after the expiration date.
- 3. All unanticipated problems must be reported to the IRB on the Event Report within 5 business days of becoming aware of the problem. Unanticipated problems are defined as events that are unexpected, related or possibly related to the research, and suggests the research places subjects or others at a greater risk of harm than was previously known or recognized. If the unanticipated problem was a death, this is reportable to the IRB within 24 hours on the Death Report.
- 4. On-site deaths that are not unanticipated problems must be reported within 5 days of awareness on the Death Report, unless the study is such that you have no way of knowing a death has occurred, or an individual dies more than 30 days after s/he has stopped or completed all study procedures/interventions and required follow-up.
- 5. All deviations (non-compliance) must be reported to the IRB on the Event Report within 5 business days of becoming aware of the deviation.
- All changes must be IRB approved prior to implementation unless they are intended to reduce immediate risk. All changes must be submitted on the Amendment Form.
- 7. All recruitment materials and methods must be approved by the IRB prior to being used.
- 8. The project-generated annual report must be submitted to the IRB for review and approval at least 30 days prior to the project expiration date. If the study is complete, the Completion/ Withdrawal Form may be submitted in lieu of the annual report.
- Securely maintain all research records for a period of seven years from the project completion date or longer depending on the sponsor's record keeping requirements.
- 10. Utilize the IRB stamped consent documents and other approved research documents located within the document storage section of eCompliance. These documents are highlighted green.

If you are offering subject payments and would like more information about research participant payments, please click here to view the MU Business Policy and Procedure: <a href="http://bppm.missouri.edu/chapter2/2">http://bppm.missouri.edu/chapter2/2</a> 250.html

If you have any questions, please contact the IRB Office at 573-882-3181 or muresearchirb@missouri.edu.

Thank you, MU Institutional Review Board

### Appendix B: Letter of Support



January 27, 2020

RE: Dissertation study of Christiana Oyewusi, PhD candidate

Dear Ms. Oyewusi,

I am pleased to support your proposed research study. The experience of living with hypertension: African American adults participating in our Live Well by Faith public health initiative. In this program we have targeted the African American population to address the health disparities of hypertension and diabetes. I understand that your research is aimed at generating a deeper understanding of the lived experience and stories of African American adults with hypertension. I understand that you will be conducting a face to face interview that will last for about an hour for those agreeing to participate in your research study. I believe that this study will be welcomed by our faith community. Our organization is committed to helping with participant recruitment and will also provide a private area in the churches where the interviews can be conducted.

I look forward to working with you.

Sincerely,

Verga Laboy, Health Educator

Live Well by Faith

Columbia/Boone Co Public Health & Human Services

1005 W Worley St Columbia, MO 65203

Verna.laboy@como.gov

(573)-874-6318

#### Appendix C: Recruitment Flyer

#### RESEARCH STUDY

What is the experience of African American adults with high blood pressure who attend a church-based wellness program in Columbia Missouri?

## To qualify you must:

- Be an African American adult (18 years old or older) who has high blood pressure
- · Attend Live Well by Faith events
- Speak English

You will be asked to participate in a 1-hour individual audio-recorded interview. You will receive a \$25 gift card for your time



Contact Christiana Oyewusi 1-573-808-7601 Appendix D: Consent Form to Participate in a Research Study (In-person)

Consent Form to Participate in a Research Study

Investigator's Name: Christiana Oyewusi; Maithe Enriquez

Project #

Project Title: The experience of living with hypertension: African American adults

participating in a faith-based wellness program.

Hypertension (high blood pressure) is a global health concern. Taking medication can control high blood pressure however, non-adherence to blood pressure medications can result in poor health outcomes. African American population has a disproportionate burden of hypertension. There is a low level of health literacy and adherence to antihypertensive agents in this population. Faith-based organizations like churches help to promote health in African American communities. Since you are an African American with hypertension, you may have important information that can help in knowing how to provide better care of your health.

We would like to ask you to participate in a study that involves research. We are asking you to take part in an individual interview. You are requested to participate in research because you are an African American adult with hypertension. We want to ask you about your experience living with hypertension and what you think about why African American adults do not take their blood pressure medicines and to suggest what to do that will help individuals African American adults take their medicines as prescribed. There are no right or wrong answers to the questions.

You are entitled to know what you will be asked to do to determine whether you want to consent to participate in the study. Being in this study is voluntary, it is your choice. You do not have to be in the study if you do not want to. If you do not want to continue to be in the study, you may stop at any time without penalty. This form may contain words that you do not know. You may ask us for explanation of any words or information that is unclear to you.

We are asking African American adults with hypertension to take part in this study. We can withdraw you from the study if need be. We would first tell you why we are withdrawing you from the study. This study will take one interview and approximately 60 minutes to complete. You may stop participating at any time without any penalty.

If you agree to be in the study, there are no direct benefits to you. You may expect to benefit from participating in the study by knowing that you are contributing to science and that study results will be used to provide better care for people. If you choose to be in the study, we will audio record the interview. We will type out your words from the recording. Your privacy is important to us. We will not use your name when we talk about the study. Any personal information that could identify you will be removed from your information. Your information may be used for future research studies without us asking for your additional permission. The recordings and other study information will be kept safely in a locked cabinet in the researchers' locked office in our University.

Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law.

There is minimal risk of being in the study. While answering the questions, you may remember some experiences related to your high blood pressure that may be upsetting. You may choose not to answer any question you do not want to answer. You can decide to stop being in the interview at any time without penalty. Being in the study is voluntary. There is no cost to you for being in the study. You also have the option of not being in this study and you will not be penalized for your decision.

You must give special written permission for use of audio recordings taken during the study. In that case, you will be allowed to listen to the audio recording before you give your permission for their use if you so request.

You will receive no payment for taking part in this study. However, you will receive a \$25 (USD) gift card.

The Principal Investigator, Christiana Oyewusi, and her collaborators do not have financial interests in the organization sponsoring this research.

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181. If you want to talk privately about your rights or any issues related to your participation in this study, you can contact the University of Missouri Research Participant Advocacy by calling 888-280-5002 (a free call), or emailing MUResearchRPA@missouri.edu

You may ask more questions about the study at any time. For questions about the study or a research-related injury, contact Christiana Oyewusi at 1-573-808-760 1. You may also contact my advisor, Dr. Maithe Enriquez at 1-816-686-3242. We would be happy to answer any questions you may have. A copy of this Informed Consent form will be given to you before you participate in the research.

#### SIGNATURES

Subject

I have read this consent form and my questions have been answered. My signature below means that I do want to be in the study. I know that I can remove myself from the study at any time without any problems.	

Date:

Appendix E: Consent with waiver of documentation for Participation in a Research Study

# Consent with Waiver of Documentation for Participation in a Research Study

Investigator's Name: Christiana Oyewusi; Maithe Enriquez

Project # 2019210

Project Title: The experience of living with hypertension: African American adults

participating in a faith-based wellness program

Hypertension (high blood pressure) is a global health concern. Taking medication can control high blood pressure however, non-adherence to blood pressure medications can result in poor health outcomes. African American population has a disproportionate burden of hypertension. There is a low level of health literacy and adherence to antihypertensive agents in this population. Faith-based organizations like churches help to promote health in African American communities. Since you are an African American with hypertension, you may have important information that can help in knowing how to provide better care of your health.

We would like to ask you to participate in a study that involves research. We are asking you to take part in an individual interview. You are requested to participate in research because you are an African American adult with hypertension. We want to ask you about your experience living with hypertension and what you think about why African American adults do not take their blood pressure medicines and to suggest what to do that will help individuals African American adults take their medicines as prescribed. If there is anything that is not clear to you as we talk, please ask me to explain. There are no right or wrong answers to the questions.

You deserve to know what you will be asked to do so that you can decide whether you want to consent to participate in the study. Being in this study is voluntary; it is your class. You do not have to be in the study if you do not want to. If you do not want to continue to be in the study, you may stop at any time without penalty. This form may contain words that you do not know. Please ask us to expatiate on any words or information that you do not understand.

We are asking about 15 African American adults with hypertension to take part in this study. We can withdraw you from the study if need be. We would first tell you why we are withdrawing you from the study. This study will take one interview and approximately 60 minutes to complete. You can stop participating at any time without penalty.

If you agree to be in the study, there are no direct benefits to you. You may expect to benefit from participating in the study by knowing that you are contributing to science and that study results will be used to provide better care for people. If you choose to be in the study, we will digitally record the interview. We will type out your words from the recording. Your privacy is important to us. We will not use your name when we talk about the study. Any personal information that could identify you will be removed from your information.

Your information may be used for future research studies without us asking for your additional permission. The recordings and other study information will be kept safely in a locked cabinet in the researchers' locked office in our University. Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law.

There is minimal risk of being in the study. While answering the questions, you may remember some experiences related to your high blood pressure that may be upsetting. You may choose not to answer any question you do not want to answer. You can decide to stop being in the interview at any time without penalty. Being in the study is voluntary. There is no cost to you for being in the study. You also have the option of not being in this study and you will not be penalized for your decision. You must give special written permission for use of digital recordings taken during the study. In that case, you will be allowed to listen to the digital recording before you give your permission for their use if you so request.

In return for your time and effort, you will receive a \$25 (USD) gift card for taking part in the study. The gift card may be sent through snail mail to your mailing address. We will need your social security number to pay you. Any payment may need to be reported as income on your tax return. If you are not a resident/citizen (non-resident alien) of the United States, you will need to work with the MU Nonresident Tax Specialist at 573-882-5509.

The Principal Investigator, Christiana Oyewusi, and her collaborators do not have financial interests in the organization sponsoring this research.

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181. If you want to talk privately about your rights or any issues related to your participation in this study, you can contact the University of Missouri Research Participant Advocacy by calling 888-280-5002 (a free call), or emailing MUResearchRPA@missouri.edu

You may ask more questions about the study at any time. For questions about the study or a research-related injury, contact Christiana Oyewusi at 1-573-808-7601. You may also contact my advisor, Dr. Maithe Enriquez at 1-816-686-3242. We would be happy to answer any questions. If you like, a copy of the consent form may be mailed to you.

You will be required to give verbal consent before you participate in the research.

If you have any questions right now, I would be happy to answer them.

Do you agree to be in the study?

# **Participant Demographic Survey**

1.	Please indicate your gender		
	Male Female Transgender		
2.	Please select the category that includes your age  18-24  25- 34  35-44  45- 54  55- 64  65 - 70  over 70		
3.	Educational level: Did Not Complete High School Completed High School Bachelor's Degree Graduate Degree		
4.	Employment status: Part -time Full time Unemployed Retired		
5.	What is your health insurance status (check all that apply)?  No insurance		
	I receive insurance through my employer.  Medicare  Medicaid		
6.	How long have you had high blood pressure?  Less than 1 year  1 to 5 years  More than 5 year		
7.	Do you have a health care provider/doctor? Yes No		

Appendix G

General Interview Guide

Guiding Questions	Follow up questions/probes
Can you please tell me your story - how did you find out that you have HTN?	In what ways has having HTN affected your life?" (social, physical, financial, emotional, physiological, work, sleep?)
Tell me what you know about HTN	What does having HTN mean to you? What does HTN do to your body if not controlled? What concerns/worries you about HTN?
Can you please tell me what your BP runs? Can you please tell me how you take care of your HTN	Tell me how you check your BP? (how often, where) What are some of your motivations for wanting to take care of your HTN?
Tell me what it is like to take your medications?	How do you work taking medications into your daily routine? What do you think helps you with your BP medications as prescribed? What challenges do you face/have you faced taking your BP medications? How did you overcome one/some of the challenges? OR are you still dealing with the challenges?
What is the information you have about managing your HTN? What things do you think might it easier to understand/use the information given to you about managing your HTN?	What information do you have about the medications you are taking for HTN? How do you get the information? How does the information help you?
Tell me about your experiences in the Live Well by Faith program	Why did you join the program? What do you like about the program? How has the LWBF program been helping you? Is there anything you would like to see added to the LWBF program?
What else do you think might help you with taking care of your health and controlling your BP?	, V
Is there anything else you would like to share?	

# HEALTH LITERACY AND MEDICATION ADHERENCE AMONG AFRICAN AMERICANS WITH HYPERTENSION

Christiana O. Oyewusi\* MSc, BSc, RN, Ph.D. Student

Maithe Enriquez\* PhD, APRN, FAAN

\*University of Missouri, Sinclair School of Nursing, Columbia, Missouri USA

Background: African Americans experience a disproportionate burden of hypertension and about half have suboptimal medication adherence. Adequate health literacy has been reported to have a positive influence on medication adherence.

Purpose: This review identified studies that examined health literacy and medication adherence among African American adults with hypertension and reports a relationship between the two variables.

Method: Databases Scopus, PubMed, and Medline Ovid were searched from the start date to August 2018. Study selection required at least 25% of the study population consist of African American adults receiving hypertension treatment.

Results: Five articles, all cross-sectional study designs, were located. One study aimed to examine the relationship between health literacy and antihypertensive medication adherence in an all-African American sample and found a significant correlation between higher health literacy and higher medication adherence. Other studies had mixed-race samples. Health literacy was reported to be lower among African Americans than other racial groups.

Conclusion: Enhancing health literacy may be a viable strategy to enhance medication adherence and improve hypertension outcomes in African American population.

However, there is a dearth of published literature that specifically focuses on the relationship between health literacy and medication adherence in this population. More research is needed.

# PROMOTORAS' PERCEPTIONS OF BARRIERS AND FACILITATORS TO MEDICATION ADHERENCE AMONG BATEY RESIDENTS WITH HYPERTENSION

Christiana O. Oyewusi\* MSc, BSc, RN, Ph.D. Student

Maithe Enriquez\* PhD. APRN, FAAN

\*University of Missouri, Sinclair School of Nursing, Columbia, Missouri USA.

Background/Significance: Hypertension is a serious public health concern affecting billions worldwide, and a risk factor for cardiovascular disease, premature death, and disability. Hypertension is the second leading cause of death in the Dominican Republic (DR), affecting nearly 35% of Dominicans. Promotoras are lay health workers making important health contributions among vulnerable, low-income, and underserved members of Latino/Hispanic populations. Jonas Batey Hypertension Program provides ongoing hypertension screening and treatment to 11 bateyes via a mobile clinic in the DR, operated by a non-governmental organization, Fundación Enciende Una Luz (Light A Candle Mission), and supported by the Dominican Republic Medical Partnership and Jonas Center. The promotoras are part of the batey community, work closely with the non-governmental organization in the program to coordinate mobile clinic visits to 11 bateyes every 3 months, and can play a key role in enhancing health outcomes among people with hypertension.

Purpose: This study explored promotoras' perceptions about the program, and barriers and facilitators to medication adherence among Dominican batey residents with

hypertension.

Research Methods: This descriptive qualitative study utilized purposive sampling to recruit six promotoras working with the non-governmental organization to deliver the Jonas Batey Hypertension Program. The program was developed through an academic-community partnership and informed by Community-Based Participatory Research methodology. Data were collected through individual interviews with promotoras in Spanish using a semi-structured interview guide. Interviews were audio-taped, transcribed verbatim in Spanish with transcripts translated to English, and analyzed using thematic content analysis. One of the investigators was fluent in Spanish and English Results: Overarching themes identified were promotoras' enthusiasm about the mobile program and feeling of making a positive impact on the health of the batey residents. The identified barrier was promotoras' inability to identify cases and enhance adherence between mobile clinics. Identified facilitators were consistent and reliable delivery of antihypertensive medications, and promotoras' reminding patients to take their medications.

Conclusions: Promotoras perceived that their work with mobile hypertension and screening program was enhancing the health of batey residents. Promotoras desired to become more engaged in screening for hypertension and provide adherence support to patients in the program.

#### **VITA**

Christiana Oyewusi obtained her Bachelor's degree in Nursing with a specialty in Nursing Education from the University of Ibadan, Ibadan Nigeria in 2000. She earned a Master of Science in Nursing with a community health nursing specialty from the same university in 2012. For over two decades, she has been engaged in clinical nursing, nursing education, and research. She worked in private and government hospitals and cred for patients with different health conditions including cardiac, obstetrics, psychiatric, and renal cases. She also taught in schools of post-basic nursing including Perioperative Nursing School, University College Hospital (UCH), Ibadan Nigeria. In 2017, she enrolled in a doctoral program at Sinclair School of Nursing, University of Missouri-Columbia. She is a member of different professional/leadership groups including The Gerontological Society of America, Griffiths Leadership Society, and American Association for Cancer Research. She has had presentations at many local and international conferences.