The Perception of Hypertension Among Haitian Adults: A Focused Ethnography

by

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ABSTRACT OF THE DISSERTATION

Perceptions of Hypertension Among Haitian Adults: A Focused Ethnography

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The terms "health disparities" and "social justice" are popular buzz words in health care. These terms have been applied locally and internationally when examining the current health conditions and health resources. Since 2010, Haiti has gained much attention from the world with relief efforts and increased attention on the apparent health needs in the country. Despite these efforts, the overall health statistics of the country have not improved (Brown, 2010; Garfield & Berryman, 2012; WHO, 2014). In 2010, in response to the global epidemiological transition, the World Health Organization (WHO) shifted its attention to worldwide non-communicable diseases (NCDs) such as cardiovascular disease, cancer, diabetes, and respiratory diseases. With this shift in attention, hypertension has been identified as a worldwide health concern. The purpose of this focused ethnography is to describe Haitians' perceptions of hypertension which contribute to the meaning of and beliefs about this chronic illness, in order to more fully understand the needs of Haitian adults with

hypertension. Kleinman's Explanatory Model of Illness (Kleinman, A., Eisenberg, L., & Good, B., (1978) serves as the theoretical background for the study. The overarching theme identified is that Haitians perceive hypertension to be a feeling that one gets which should be treated at that moment to prevent falling down. This feeling presents differently and can vary with occurrences and individuals. The feelings identified as being associated with hypertension can actually be a variety of symptoms to include: headache, blurry vision, dizziness, burning, weakness, and shortness of breath. These feelings, known as symptoms in allopathic medicine, are consistent with presenting clinical manifestations of hypertension as well as consistent with the complication of stroke often associated with uncontrolled hypertension. The findings in this study can be expanded upon to inform management and treatment options for this population as well as provide recommendations for healthcare providers serving in developing countries.

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CHAPTER I

Introduction and Theoretical Perspective

The terms “health disparities” and “social justice” have become buzz words in health care within the last decade. These terms have been applied locally and internationally when examining the current health conditions and health resources. My journey into gaining a first-hand perspective of health disparities began in 2009 with a trip to the border of the Dominican Republic and Haiti. The lack of basic resources such as food, clean water, and shelter opened this writer’s eyes and heart to the health care needs of those living not too far from the United States. This was the first of a series of return visits to the country of Haiti to offer basic nursing care and education to residents in rural areas of Haiti. The healthcare needs are abundant in rural areas of Haiti where many walk miles to find a clinic that offers medical care. My second trip to Haiti came 6 weeks after the earthquake in January 2010. Some of the more prevalent health conditions that were evident with the first encounter and verified with each subsequent visit included malnutrition, parasitic infections, dermatologic conditions, headaches, and hypertension. Since 2010, Haiti has gained much attention from the world with relief efforts and increased attention on the apparent health needs in the country. Despite these efforts, the overall health statistics of the country have not improved (Baptiste et al., 2018). The resources remain limited and the health care needs remain great.

Haiti's population is estimated to be 9.6 million with 80% of those living below the poverty line and a literacy rate of 52.9% (Central Intelligence Agency, 2010). Control of infectious diseases such as malaria, typhoid fever, bacterial diarrhea, tuberculosis, and HIV/AIDS has historically been an area of focus for international healthcare organizations providing care in developing countries (World Health Organization, 2014). In 2010, in response to the global epidemiological transition, the World Health Organization (WHO) shifted its attention to worldwide non-communicable diseases (NCDs) such as cardiovascular disease, cancer, diabetes, and respiratory diseases. With this shift in attention, hypertension has been identified as a worldwide health concern.

The purpose of this study is to describe Haitians' perceptions of hypertension which contribute to the meaning of and beliefs about this chronic illness, in order to more fully understand the needs of Haitian adults with hypertension. The overarching question of this study is: What are the perceptions regarding hypertension in the Haitian population that contributes to the meaning of and beliefs about this disease?

Theoretical Perspective

Kenerson (2014) published a review paper examining the problem of hypertension in Haiti and best practices regarding treatment of the disease. Kenerson reviewed the prevalence of hypertension in Haiti (using both published and unpublished data), contributing factors, and possible strategies for management of the disease moving forward. The enormity of hypertension in

Haiti led him to ask, “Why is the management of hypertension in this community so difficult?” (Kenerson, 2014, p. 111).

Consistent with Kenerson’s question posed above, the initial review of the literature coupled with personal experiences in Haiti, led to a desire to understand the perceptions of hypertension in this unique population. The work of medical anthropologist, Arthur Kleinman and his focus on Explanatory Models of Illness (EM) serves as the theoretical framework for this study to examine individual beliefs and perceptions within a culture. Kleinman’s work explains the EM as a set of core beliefs comprised of five domains: etiology (psychosocial, biomedical, or combination of the two); onset of symptoms (when to seek healthcare); pathophysiology (labeling and explaining the illness); course of illness (healing practices); and treatment outcomes (Young, 1982). Kleinman believes that a substantial proportion of healthcare (70%-90%) occurs outside of the formal setting and more in “folk” settings which may include self-treatment rituals, family care, self-help groups, religious practitioners, folk healers, etc. (Kleinman, Eisenberg, & Good, 1978). Kleinman also suggests that EMs are highly individual within cultures and dynamic over time as the illness/disease changes and the person becomes more knowledgeable about their condition.

Phenomenon of Interest: Perceptions of Hypertension in Haiti

The WHO identifies hypertension as the most preventable form of death, estimating deaths due to cardiovascular disease will increase from 17 million in 2008 to 25 million in 2030 (WHO, 2014). Hypertension has been identified as the primary modifiable risk factor in 51% of stroke deaths and 45% of coronary heart

disease deaths (WHO, 2014). Mortality data for Haiti indicates that the country has the highest reported stroke rate in North America and one of the highest reported stroke rates in the world, at 176 per 100,000 or 10.3% of deaths (World Life Expectancy, n.d.). In addition, hypertension contributes to the development of atrial fibrillation, congestive heart failure, renal disease and retinopathy. Statistics related to mortality rates as a result of cardiovascular disease in Haiti are difficult to track however, Kenerson (2014) reports that the death rate related to complications from hypertension in Haiti to include stroke and other complications such as renal disease can be as high as 20%. Despite these other complications and statistics, research examining the perceptions of Haitian adults concerning hypertension is noticeably lacking. According to the WHO, 48% of NCD deaths worldwide are attributed to cardiovascular disease (WHO, 2014). In response, the WHO has focused their attention on behavioral risk factors and interventions to combat these alarming statistics in developing countries where deaths from cardiovascular diseases now surpass deaths from communicable diseases. The most recent statistics posted by the WHO report Haiti with 545/100,000 deaths from communicable diseases and 697/100,000 deaths from non-communicable diseases in 2008 (WHO, 2014). Eighty percent of all NCD deaths worldwide occur in low- and middle-income countries among people younger than 70 years of age, compared with an estimated 26% in high income countries (WHO, 2014). According to the WHO 2014 statistics, 342 per 100,000 residents of Haiti die between the ages of 30 and 70 years as a result of cardiovascular disease. This number is similar to that of other developing

countries such as Cambodia (384/100,000); Cameroon and Ethiopia (473/100,000); and South Africa (307/100,000). Mortality data from these countries are approximately three times greater than that of the United States (137/100,000). This is regrettable, because hypertension is a modifiable health condition; with proper control, it is possible to reduce HTN-related morbidity and mortality. It is necessary to understand the perceptions of hypertension among Haitian adults as a first step to promoting adherence to treatment protocols and decreasing the risk of hypertension-related cardiovascular disease in this population. Strategies are needed that enhance Haitians' abilities to successfully manage this modifiable health condition. However, it is necessary to first determine the perceptions of and beliefs about hypertension in order to elucidate the meaning of hypertension within this particular cultural group. This study will examine the perceptions of hypertension in Haitian adults to serve as a foundation for future successful development of strategies to aid in the care and control of this chronic condition.

Foundational Assumptions

Although hypertension is a modifiable health condition, its growing prevalence in Haiti suggests that strategies aimed at reducing prevalence and complications of hypertension cannot be solely left to pharmaceutical interventions. Research suggests that conditions such as hypertension may have specific cultural factors impacting care and control of the disease. Furthermore, these sociocultural factors (self-treatment regimens, folk healers, religious practices, limited resources, limited knowledge of, etc.) may be present in the

Haitian population, thus impacting care and control of hypertension in those affected. The first step to developing strategies to reduce hypertension in the Haitian population is to gain a further understanding of perceptions and beliefs regarding the disease and treatments, both pharmaceutical and non-pharmaceutical in the identified population. This understanding can be gained through formal and informal conversations as well as direct observations.

This study will be a *Focused Ethnography.* As a method of qualitative inquiry, focused ethnography is gaining popularity in nursing research in order to focus on a distinct issue or shared experience in cultures in specific settings. Roper and Shaper (2000) identified the following three main purposes of focused ethnographies: (1) to discover how people from various cultures integrate health beliefs and health practices into their daily lives; (2) to understand the meaning that members of a subculture or group assign to their experiences; and (3) to study the practice of nursing as a cultural phenomenon. This approach will allow for in-depth focus of hypertension in the Haitian adult population with specific attention to sociocultural factors that may impact care and control of the disease.

Significance of Study

Primary health care in rural Haitian communities is often provided on a short-term basis by practitioners from other countries through medical mission work. Unfortunately this arrangement does not allow for comprehensive follow-up care of chronic illnesses such as hypertension. Although non-government organizations (NGOs) based in the country are available in areas to provide ambulatory primary care, little is known about rural Haitians' perceptions of

hypertension as an acute or chronic disease. There is limited but compelling data confirming the prevalence of hypertension in Haiti. Data from rural clinics from 2000-2010 suggests hypertension to be prevalent in 39% of men and 45% of women (Lluberas, Parrish, & Kling, 2000; Niska & Sloand, 2010). This data is consistent with that of the 2014 statistics from the WHO, which reported 33.6% of males and 28% of females over the age of 25 years in Haiti have increased blood pressure (WHO, 2014) and from later research reporting overall prevalence rate in rural Haiti to be approximately 34.4% (Polsinelli, Satchidanand, Holmes, & Izzo Jr, 2017). Unpublished data reports that the percentage of hypertension among Haitian adults is as high as 69% for men and 67% for women in urban areas such as Port-au-Prince (Baptiste et al., 2006; Kenerson, 2014). These numbers support the need to develop strategies that address care and control of hypertension in Haiti. However, without a true understanding of health beliefs and practices regarding hypertension, successful management of this growing health condition will be difficult to achieve.

What most individuals in the US consider “traditional” healthcare (care received in established physician practices as opposed to temporary volunteer run clinics) is typically only available in Haiti to individuals who can pay for services. There is no formal type of national health care in Haiti and since most Haitians are self-employed, health insurance is non-existent. As a result, many poor Haitians suffer needlessly from undiagnosed or underdiagnosed illnesses, including hypertension. Many Haitians die without formal medical care or a formal diagnosis of cause of death (Etienne & Pavlovich-Danis, 2013). In addition, Haiti

is not considered to be a future- oriented society. According to Etienne & Pavlovich-Danis (2013), day to day survival supersedes thoughts of the future and the possible long term impact of medical conditions such as hypertension, particularly if no symptoms are present. Hypertensive individuals who are oriented to the present may not seek healthcare until complications, such as stroke, occur. With limited healthcare resources in these rural areas, death or impaired quality of life is often the outcome of this potentially modifiable health condition. These are examples of socioeconomic and cultural factors which may contribute to the high prevalence of hypertension in Haiti.

Further exploration is needed to gain a full understanding of hypertension for the Haitian adult in order to develop effective treatment strategies that are culturally relevant. Consistent with the epidemiological transition (Orman, 1971), the literature has shown that hypertension and cardiovascular disease are increasing rapidly in developing countries where resources are limited (Baptiste et al., 2018; Kenerson, 2014; Polsinelli et al., 2017; Suhrcke, Boluarte, & Niessen, 2012). Kenerson and colleagues have focused their efforts on formulating “Best Possible Practice” models of care in which they bridge evidence-based medicine and reality-based medicine as a result of limited resources (Kenerson, 2014). The WHO has made commitments to lower deaths from non-communicable diseases worldwide. A key step in the process of addressing the prevalence of hypertension in Haiti is to examine its meaning and how Haitians’ currently perceive self-management of hypertension.

Purpose of the Research

The aim of this focused ethnography is to more fully understand the perceptions of hypertension for participants within a rural Haitian village who have been diagnosed with hypertension. Determination of Haitians' perceptions that contribute to beliefs about and the meaning of hypertension may lead to an understanding of the barriers to hypertension care and control in this underserved population. Data from the community clinics have documented the prevalence of hypertension in rural areas of Haiti but have not provided information that can provide practitioners insight into how Haitians perceive this health condition, treatment, and complications as a result of non-treatment.

Definition of Terms

Perceptions, beliefs, and meanings are terms that will be used throughout the study. For the purposes of this study they are defined here using the Merriam-Webster Online Dictionary (http://www.learnersdictionary.com).

Perception is defined as, "the way you think about or understand someone or something" (http://www.learnersdictionary.com/definition/perception). Belief is defined as, "the reality of some being or phenomenon especially when based on examination of evidence" (http://www.learnersdictionary.com/definition/belief). Meaning is defined as, "the purpose of something, a quality that gives something value and importance, or the reason or explanation for something" (http://www.learnersdictionary.com/definition/meaning).

These definitions will be used to guide this study in conjunction with Kleinman's premise that an Explanatory Model (EM) is the reframing of patients'

beliefs and perceptions which are defined as “the patients’ understanding of the cause, pathophysiology, course of illness, symptoms, and effects of treatment”(Bokhour et al., 2012, p. 1627).

Conclusion

This focused ethnographic study will describe Haitians’ beliefs about hypertension and the meaning of hypertension. The intended audience for this study includes clinicians practicing in Haiti as well as in other developing countries and those teaching in nursing programs. Data will be collected through participant observation; individual, semi-structured interviews with Haitian adults identified in a community clinic in Domond, Haiti; and document collection. The interviews and observations of the participants will provide detailed descriptions about knowledge of hypertension, awareness of complications of hypertension, self-management strategies, and perceived barriers to care (resource availability of medications and regular health care). As these areas are explored through focused ethnography, the beliefs about and the meaning of hypertension in the Haitian population may emerge.

CHAPTER II

Review of the Literature

The purpose of this literature review will be to provide background of the phenomenon of interest in Haiti as well as in other developing countries in regards to prevalence, risk factors, and sociocultural implications that may impact care and control of the disease. Furthermore, Kleinman's Explanatory Model of Illness will be discussed as the theoretical framework for this focused ethnography on the perceptions of hypertension among Haitian adults. This review of the literature will illuminate gaps in the empirical literature and research questions will be presented.

Importance of Studying Hypertension in Haiti

Hypertension is an emerging global health concern, with greater than 25% of the world's adult population having a blood pressure ≥ 140/90 (WHO, 2014; Mittal & Singh, 2010). Hypertension is a preventable disease, for which screening is readily available, even in countries with limited resources (Mittal & Singh, 2010). The improvement of screening and treatment adherence in developing countries is critical to prevent complications from untreated hypertension. Complications can be deadly and/or debilitating and costly for an already economically strained population. Complications from untreated hypertension include cardiovascular disease, kidney disease, and stroke (Kearney et al., 2005; Ibrahim & Damasceno, 2012). Kenerson (2014) suggests one might argue that

hypertension and hypertension-related diseases (stoke and renal mortality) are responsible for up to 20% of deaths in Haiti.

The purpose of the study conducted by Mittal and Singh was to review data about the epidemiologic characteristics and risk factors for hypertension in the developing world. They found that regardless of country, one common barrier identified was lack of disease awareness. Furthermore, several variables were identified that are associated with contributing to this lack of awareness in developing countries. These include lower social class, lack of health care facilities, and limited financial resources (Mittal & Singh, 2010). Mittal and Singh address these barriers to diagnosis and treatment in populations living in multiple developing countries.

The research of Mittal and Singh will be considered when examining beliefs about and perceptions of hypertension in Haiti. Their research suggested that lower social class, lack of health care facilities, and limited financial resources are variables that remain constant in developing countries. Haiti has the largest proportion of people living in poverty and the highest mortality rate of any country in the Western Hemisphere. In contrast to other countries in the Americas, per capita income in Haiti has declined by half over the last two decades. Most Haitians live on less than $1.25 American dollars per day (Garfield & Berryman, 2011). Kenerson (2014) breaks the statistics down further, reporting that 75% of the Haitian population lives on less than $2 per day, with 56% of those living on less than $1 per day. In addition, healthcare resources are minimal. There are approximately 2.8 healthcare workers, physicians and nurses

combined, per 1000 inhabitants in Haiti. This is one-fourth of the world's average and one-tenth of the average for North America (Garfield & Berryman, 2011). As a result of limited Haitian healthcare workers, charitable and non-governmental organizations are the major providers of health services in Haiti (Garfield & Berryman, 2011). Furthermore, according to the Pan American Health Organization (PAHO), Haiti had 0.8 hospital beds per 1000 patients in 2007, as compared to 3.2 in the United States and 4.9 in Cuba (Kenerson, 2014).

An exploration of the meaning of the term *awareness* is critical to an understanding of how individuals acknowledge the presence of a disease. Awareness of hypertension may refer to the knowledge that one has hypertension, or it may refer to an understanding of the pathology of hypertension. Either form of awareness has potential to be mediated by the three aforementioned variables identified by Mittal and Singh (2010). A lack of knowing that one has hypertension can be attributed to a lack of appropriate healthcare screenings visits; which in turn, is a result of limited healthcare facilities in particular areas. Lack of financial resources may lead to inability to pay for services that can identify health conditions. Mittal and Singh found that in developing countries, lack of awareness is linked to lower social class and limited resources. These factors are barriers to the diagnosis and treatment of hypertension. Although their research sheds some light on contributing factors, there is no discussion of the actual beliefs about or meaning of hypertension in the countries studied. Mittal and Singh do not explore the relationship of awareness of an illness and the meaning assigned to an illness once aware.

The meaning of an illness is derived from cultural beliefs and practices as well as environmental factors (Nabolsi & Carson, 2001; Rose, Kim, Dennison, & Hill, 2000; Strahl, 2003). Cultural practices, in particular religious and spiritual beliefs, are often key components in assigning meaning to disease. A study of Jordanian Muslim men found that religious beliefs shaped their meaning of illness, suffering, and dying as a part of life, a test from Allah, and suffering from illness as atonement for their sins (Nabolsi & Carson, 2011). In Tanzania, one patient described hypertension as "*presha* that is a result of emotional, hurt feelings from the soul" (Strahl, 2003, p 315). When examining various cultures and adherence, Rose et. al (2000), found that African American men felt seeking treatment was a sign of being 'weak' or 'not macho'. Furthermore, environmental factors associated with low socioeconomic status, lack of education, and lack of health care resources in rural areas has also been found to contribute to meaning of disease. Such factors ultimately contribute to the lack of knowledge of disease existence and pathology (Higginbottom, 2006; Rose et al., 2000; Strahl, 2003).

Researchers have demonstrated that the experience and the meaning of a diagnosis of hypertension is mediated by existing social, economic, and cultural influences in a person's life (Higginbottom, 2006); and that understanding the relationship of these variables to the meaning of disease will aid in the development of culturally competent strategies. This premise underscores the importance of studying hypertension in Haiti and is consistent with Kleinman's EM theory which serves as the theoretical foundation for this study.

Searching the Literature

Although hypertension in Haiti is a growing concern, limited research has been conducted to date in this population (Baptiste et al., 2018). A literature search was conducted using CINAHL, PUBMED, and MEDLINE. The initial literature search included the following terms: Haiti, hypertension, chronic illnesses, and non-communicable diseases prior to and during the study. This search yielded a total of 27 articles for review with a mixture of focus from hypertension in pregnancy, the need for dialysis in Haiti, and prevalence studies. Of these 27 articles reviewed, five were chosen for review in this study based on their focus of hypertension in the non-pregnant Haitian adult (Baptiste et al., 2006; Etienne & Pavlovich-Danis, 2013; Kenerson, 2014; Lluberas, Parrish, & Kling, 2000; Niska & Sloand, 2010). To learn more about hypertension care and control, the search was then broadened to examine hypertension care and control in vulnerable populations in general. This search yielded numerous results for various populations worldwide, most focusing on barriers to hypertension treatment with little to no emphasis on cultural aspects of the chronic disease in Haiti.

To gain a better understanding of cultural practices in Haiti that may contribute to hypertension or impact care and control in this population, additional search terms of culture, Haiti, and health literacy were used to search CINAHL and PUBMED. There is a paucity of published research studies that address hypertension in Haiti from a cultural perspective (Baptiste et al., 2006; Kenerson, 2014; Lluberas, Parrish, & Kling, 2000). Again, as a result of limited research

found, an additional search of anthropology, sociology, and religious databases was conducted using the following combinations of search terms: health beliefs and Haiti; health beliefs, Haiti, and hypertension. This expanded search yielded an additional three articles to culture in Haiti but none specific to hypertension in Haiti (Nicolas, DeSilva, Grey, & Gonzalez-Eastep, 2006; Khoury, Kaiser, Keys, Brewster, & Kohrt, 2012; Vonarx, 2011).

Risk Factors and Prevalence of Hypertension in Haiti

Since the earthquake of 2010, the world has become more aware of Haiti's needs. As a result, many countries have offered aid to improve the infrastructure of the country and create opportunities for the Haitian population to sustain themselves through increased jobs and resources (Garfield & Berryman, 2011). With such opportunity come changes in lifestyle, some positive and some negative. For example, as developing countries become more urbanized, lifestyle changes impact the rise of hypertension among these populations (Strahl, 2003). Urbanization is associated with unhealthy lifestyle changes such as an increase in sedentary lifestyle, increased accessibility to unhealthy food choices, and an increased use in tobacco and alcohol (Dennison et al., 2007; Kearney et al., 2005; Mittal & Singh, 2010). The mere fact that Haiti is a developing country is also a risk factor in itself. Of the estimated 972 million adults with hypertension worldwide, 639 million are in developing countries (Kearney et al., 2005). Furthermore, low- and middle- income countries account for 80% of hypertension related disease and yet only have access to about 10% of the global resources to manage the disease and its complications (Kenerson, 2014).

Haiti is a unique blend of a country which remains largely rural, while simultaneously facing issues of urbanization within the capital of Port-au-Prince. The capital region is home to approximately 2 million inhabitants or 25-30% of Haiti's total population (Garfield & Berryman, 2011; Niska & Sloand, 2010). The population of Port-au-Prince has not grown significantly since the earthquake; however, the city and surrounding areas still face many of the risk factors related to urbanization that are worthwhile of further examination and consideration for future impact on population health.

Baptiste and colleagues (2006) examined the prevalence of diabetes and other cardiovascular risk factors in Haitians living in Port-au-Prince from September 2002 to May of 2003. The study included 331 men and 782 women. Of these, 10.5% of men and 9.1% of women were found to be pre-hypertensive according the JNC-7 guidelines, while 48.7% of men and 46.5% of women were found to be hypertensive. The purpose of this cross-sectional survey was to examine the prevalence of diabetes and its relationship with other cardiovascular risk factors such as hypertension. Data was collected from completed questionnaires as well as, anthropometric, blood pressure, and glucose measurements. Baptiste established that there is a positive relationship between hypertension and the development of diabetes in the Haitian population. Unfortunately, there have been no other published studies related to urbanization and chronic health conditions in Haiti since this time.

Just as urbanization may impact the health of the population, rural areas of developing countries are faced with other challenges that create an increased

risk for hypertension and long- term health conditions. Studies have identified risk factors of cardiovascular disease in the rural areas in developing countries such as Haiti. Factors increasing the risk of cardiovascular disease include tobacco use and smoke ingestion from charcoal fires or domestic fuels, increased stress, poor nutrition, and alcohol consumption (Ibrahim & Damasceno, 2012; Mittal & Singh, 2010). Haiti's countryside is home to many remote areas where people typically must walk for hours on rough roads and trails to be seen at a clinic (Niska & Sloand, 2010). Seventy percent of the nurses work in Port au Prince, leaving the remaining two-thirds of the population with very limited access to nursing care. In addition, it is estimated that there is one physician per 10000 inhabitants in Haiti (Garfield & Berryman, 2011).

A search of the literature yielded one study of hypertension in rural Haiti. Niska and Sloand (2010) focused on ambulatory care rendered in rural Haitian clinics during a one- week span in 2005. This descriptive study was conducted in Léon, Haiti where medical mission volunteers have been targeting hypertension control as a goal of care for this population since 1997. Data was collected during the intake assessment by nurses and emergency medical technicians and recorded on forms already in use at the clinic. Hypertension was the second most common problem affecting older adults in this population. Because of the potential for complications as a result of uncontrolled hypertension, the disorder was chosen as an area of concentration for these researchers. Their study identified common barriers to the successful treatment of hypertension in the rural Haitian population, such as running out of medication, choosing medication

regimens based on availability of donated medications on hand, family and environmental factors that prevent patient from returning as scheduled for follow-up, lack of consistent ongoing health education in these rural areas, and treatment based on rigorous protocols to prioritize higher risk patients for treatment as a result of limited resources (Niska & Sloand, 2010). Niska and Sloand (2010) recognized that their study is limited to data collected from just one week's worth of clinics in one rural area of Haiti. However, despite the limited sample, time frame and location, the findings remain consistent with other researchers who also found high rates of hypertension in other Haitian communities (Baptiste et al., 2006; Etienne & Pavlovich-Danis, 2013). This study emphasizes that in order to maximize healthcare for hypertensive Haitians, further research is needed that investigates beliefs that may lead to barriers to treatment (Niska & Sloand, 2010).

Researchers and Haitian clinicians are concerned about the long- term health of the Haitian population given the complications of uncontrolled hypertension and the complexity of caring for this particular population. Niska and Sloand (2010) reported that a more in- depth analysis of beliefs about hypertension care and control will be helpful in uncovering information that may assist in developing future educational programs for the Haitian clinicians and patients.

Relevance of Hypertension Worldwide to Hypertension in Haiti

Despite the lack of literature addressing Haiti specifically, uncontrolled hypertension in other developing countries is emerging as the leading cause of

death and disability (Kearney et al., 2005; Mittal & Singh, 2010). Two-thirds of the adult populations world-wide identified with hypertension are from developing and under-developed countries with an expected increase to three-quarters by 2025 (Mittal & Singh, 2010). Reasons for this increase in hypertension in developing countries have been attributed to lifestyle changes as a result of urbanization; racial and ethnic differences; growth and development in utero, infancy, and childhood; poverty; and behavioral choices such as tobacco and alcohol use.

Hypertension is a growing economic burden in developing countries with already strained resources (Kearney et al., 2005). Uncontrolled hypertension results in increased death and disability rates as a result of stroke, kidney disease, and cardiovascular disease. When healthcare is available, treatment is costly and the complications often have the long term impact of limiting the person's ability to provide for their family. In a more economically developed country such as the United States, the average annual cost for uncontrolled hypertension is estimated to be five times higher than the average annual cost for controlled hypertension (Li, Stotts, & Froelicher, 2007). The economic impact in a developing country is unknown, but likely to have similar economic insult relative to the country. Contributing to this growing economic burden is lack of awareness of disease leading to lack of treatment and control. Three quarters of people with hypertension (639 million people) living in developing countries have very little awareness of the chronic disease and even less about how to control it (Ibrahim & Damasceno, 2012). Consequently, the onset of cardiovascular

disease occurs at an earlier age in developing countries (Kearney et al., 2005). Because of the scarcity of resources in developing countries, population-wide health strategies addressing hypertension would be more cost-effective in reducing complications of disease. Kearney et al. (2005) suggest that targeting primary prevention in these populations is just as important as increasing the awareness, treatment, and control of hypertension. Ibrahim and Damasceno (2012), note that between 1990 and 2020, mortality from ischemic heart disease in developing countries will rise by 120% for women and 137% for men. The literature also reports that two thirds of all strokes and half of all coronary artery disease can be directly linked to non-optimum blood pressure control globally (Perkovic, Huxley, Wu, Prabhakaran, & MacMahon, 2007).

With limited financial health care resources in Haiti, there is a need to develop cost effective strategies that can reduce the prevalence of hypertension and its associated complications. Suhrcke, Boluarte, and Niessen (2012) conducted a systemic review on economic evaluations of interventions to combat cardiovascular disease in low and middle- income countries. The authors found that the evaluation of cost-effective strategies to combat cardiovascular disease in developing countries is lacking and that the focus is mainly on pharmaceutical interventions. Suhrcke et. al (2012) suggests that the most cost-effective approaches should be aimed at primary prevention strategies in these low- to middle-income countries. Research is needed to determine “what works” in these limited resource populations in order to impact long term care and costs of cardiovascular diseases (Suhrcke et al., 2012). Colleagues in Care, an

organization of healthcare providers in Virginia Beach, Virginia, has begun work to combat hypertension in Haiti with a “Best Possible Practice” care model that considers the limited resources, the culture, and the infrastructure of healthcare in Haiti (Kenerson, 2014). Colleagues in Care has recently implemented a Haiti Hypertension Program with the goal of developing guidelines for management of care that are culturally appropriate for this limited resource country.

Hypertension Worldwide: Universal Risk Factors

Although risk factors leading to hypertension vary in populations, they can be categorized as genetic, behavioral, or environmental. There are two sets of risk factors associated with HTN: 1) risk factors affecting incidence (ex: genetics) and 2) risk factors affecting control (ex: access to medications). Genetic factors present in non-Hispanic Blacks have been attributed to the degree of sensitivity one has to salt; leading to increased salt retention thereby increasing incidence in this population (Saunders, 2009). The current evidence is clear that HTN is a complex condition comprised of multiple genetic and environmental factors (American College of Cardiology/American Heart Association Task Force on clinical Practice Guidelines, 2017). Ibrahim and Damesceno examined the prevalence of hypertension between persons of African and European origin and found that after controlling for socioeconomic status, there was no association between race and the incidence of hypertension. Environmental risk factors impacting the control of hypertension in populations living in developing countries include poverty, lower educational levels, and decreased access to health services (Ibrahim & Damasceno, 2012; Kearney et al., 2005; Mittal & Singh,

2010). Behavioral risk factors for development of hypertension include smoking, heavy alcohol consumption, poor dietary habits, and physical inactivity (Pantell, Prather, Downing, Gordon, & Adler, 2019; Suhrcke et al., 2012).

Lack of awareness of disease pathology and prevention can be one of the biggest risk factors for poor hypertension control. Rates of hypertension awareness, treatment, and control were examined in the developing countries of Egypt, Tanzania, South Africa, Ghana, China, Mozambique, and Vietnam (Ibrahim & Damasceno, 2012). Ibrahim and Damaceno (2012) compared their findings with rates of awareness, treatment, and control in developed countries. These researchers found the extent of awareness is much lower in developing countries, resulting in fewer primary prevention strategies and lack of public health policies regarding hypertension screening and treatment. Ironically, it is the primary prevention strategies that may have the most impact on disease prevention and management simply by increasing the level of awareness (Suhrcke et al., 2012). Following the cholera outbreak of 2010 in Haiti, Suhrcke et al. conducted a study to assess the effectiveness of interventions to prevent the spread of cholera. Their findings indicated that primary prevention strategies such as public messaging were successful in promoting behavior changes to address the threat of cholera, particularly in increasing acceptance of drinking chlorinated water. This is significant in that it does show that with an increase in knowledge and awareness, disease outcomes and prevalence have been positively impacted in the Haitian community.

Hypertension, unlike diabetes, may have an asymptomatic component that can pose an added barrier to education strategies aimed at the care and control of the disease. For example, with diabetes there are obvious physical symptoms such as polydipsia, polyuria, and polyphagia, which cue a person to take action to combat the illness. With hypertension, physical symptoms may not exist or may not be directly attributed to hypertension and therefore, impact the cue to act. An examination of the meaning and beliefs about hypertension may provide valuable information that can drive primary prevention strategies aimed at reducing prevalence and complications. Do Haitians only seek treatment or continue treatment for diseases that present with symptoms? Is there a lack of meaning assigned to asymptomatic diseases? In developing countries such as Haiti, health care is focused on the daily illnesses and diseases that present with symptoms impacting daily functioning. Gaining an understanding of the beliefs about and the meaning of hypertension (or lack of meaning) is the first step in addressing the prevalence of hypertension in Haiti.

Health Beliefs Related to Religion and Culture in Haiti

One of the challenges presented in studying illness in varying countries, both developed and developing, is the variety of ethnic groups, health beliefs, and health practices that are encountered. Treatment plans, resources, and options vary greatly from country to country, community to community. Despite the universality of hypertension as a chronic disease, an easy “fix” in one country is not always transferable to another. Culture directly impacts health care beliefs which in turn impacts treatment and control. Culture impacts beliefs related to:

the health care system, the role of folk healers, the causes attributed to illnesses, and their reactions to illnesses (Strahl, 2003). There is a need to understand and recognize the patients' perspective of illness, symptoms, and ideal treatment regimens in order to establish treatment guidelines that best fit the needs and beliefs of a particular population (Kolb, Zarate-Abbott, Gillespie, Deliganis, & Norgan, 2011; Strahl, 2003).

An exploration of the particular health beliefs and practices in Haiti was the first step in an attempt to gain an understanding of potential influences on medical practices in this country. Vonarx (2011) completed a 16- month ethnographic study on the role of voodoo in Haiti as a *health care system*. Vonarx reports that in the literature, voodoo is generally known as an African American religion that involves the use of priests, fraternities, sanctuaries, and rituals to recognize the spirits, ancestors, and the dead. However, this depiction of voodoo does not account for the therapeutic dimension that is often present in Afro-Caribbean religions (2011). In Haiti, where voodoo is thought of as a health care system, disease and illness management may incorporate some of these practices. Vonarx asserts that "illness management is the most important aspect of voodoo" (p. 45). This study illuminates that voodoo as a healing practice is worthy of consideration when examining illness beliefs in this population. Vonarx suggests a number of factors which may influence the popularity of voodoo in the health care practices of the Haitian population. Haitian voodoo is organized, coherent, and socially rooted in the society, with practitioners recognized as a type of healer. Although different than medically- based practitioners, spiritually-

based voodoo practitioners also have specified treatment sites and practice according to protocols. Voodoo offers plans for illnesses that are therapeutic, care-giving, and preventative and are based on the theories of voodoo. Furthermore, the Haitian government recognizes voodoo as a bona- fide religion and the most important tenet of voodoo is healing people from sickness (Etienne & Pavlovich-Danis, 2013). The literature does not specify the perspective of voodoo on hypertension or its treatment in Haiti.

It is also important to consider culture when examining possible non-adherence with particular patients. Some patients may feel that their illness is a necessary suffering for the wrong they committed and that treatment is not acceptable (Etienne & Pavlovich-Danis, 2013; Vonarx, 2011). A study focusing on mental health treatment in Haiti recognized that voodoo is a cultural practice in which a person views themselves as existing as part of a larger universe consisting of divine spirits, ancestors, social relationships, and the natural world (Khoury, Kaiser, Keys, Brewster, & Kohrt, 2012). Because the meaning of the illness itself may be rooted in deep cultural practices, voodoo as a possible alternative treatment or an adjuvant to medical treatment cannot be dismissed when caring for the Haitian population. However, the findings of Khoury et. al (2012) also suggest that the lack of material resources and infrastructure in these rural areas may possibly be the reason for rural Haitians using voodoo as a "*de facto* health system" as opposed to strong religious and cultural beliefs.

To further examine health practices that contribute to hypertension in Haiti, a search of the literature was conducted to determine the role of diet,

stress, and physical activity in this particular population. PubMed, CINAHL, anthropology, and sociology databases were searched using the following terms: health, culture, diet, stress, activity, and Haiti. No further studies where found that examined these behavioral and cultural influences on health and hypertension in the Haitian population. This gap in the literature further supports the need for this focused ethnography on hypertension in Haiti.

Theoretical Rationale

Arthur Kleinman's Explanatory Models of Illness will serve as the theoretical rationale for this focused ethnography. The literature review included a search of the anthropology database with the following search terms: explanatory models and hypertension. This search yielded three articles specific to Haiti or Haitian immigrants (Khoury et al., 2012; Mazzeo, 2013; Nicolas et al., 2006); three articles specific to EM and hypertension in vulnerable populations (Bokhour et al., 2012; Dela Cruz & Galang, 2008; Taylor et al., 2012); and three articles relevant to the use of EM in general (Kleinman et al., 1978; Lynch & Medin, 2006; Young, 1982).

Explanatory Models of Illness "simultaneously create order and meaning, give plans for purposive action, and help to produce the conditions required for their own perpetuation or revision" (Young, 1982, p. 267). EMs of hypertension of those living within Haiti has not been explored in the literature. However, a review of the literature found support for its use with Haitian immigrants when examining hypertension. EMs have been explored in Haiti in regards to seeking mental

health care. EMs have also been useful in examining hypertension in other minority and vulnerable populations.

Hypertension self-management was explored using the patients' explanatory model in a qualitative study completed in two large US Veterans Affairs (VA) medical centers. Semi-structured interviews of 48 participants identified as having a blood pressure ≥ 140/90 were conducted using the premise that EMs are useful in providing a patient centered approach that incorporates how patients understand hypertension, attempt to manage hypertension, and prioritize their management of hypertension (Bokhour et al., 2012). The results of their qualitative study found that four different components of EMs were evident in their interviews: beliefs regarding the cause of hypertension, hypertension symptoms, the illness course, and treatment value/effects. Of particular interest was that the biomedical or pathophysiological explanation for hypertension played a very small role in the self-management practices (Bokhour et al., 2012). Rather, self-management was found to be related to perceptions of cause, illness course, symptoms, and treatment. Participants identified causes of hypertension to be related to stress, exercise, and/or pain, as opposed to pathophysiological causes of hypertension. Self-management behaviors aimed at controlling hypertension did not differentiate between chronic hypertension and situational hypertension brought on by things such as stress, pain, and exercise. Participants discussed the course of hypertension as intermittent, not able to be controlled, as having no impact on life, and variations in what is considered as "high". When exploring symptoms as part of the EM, some reported headaches

and dizziness when blood pressure is high and others reported no symptoms at all. Exercise and use of garlic and vinegar were prevalent in the treatment aspect of patients' EMs (Bokhour et al., 2012). The overall results of this study indicated that patients' reports of their EMs and beliefs about hypertension are more relevant to their self-management behaviors than interactions that occur in the formal healthcare setting. Bokhour et al. (2012) suggest that a patient centered approach calls for strategies that address the complex social and behavioral aspects of chronic disease self-management. A patient centered approach will incorporate the patient's understanding of the disease and prioritize management strategies around individual beliefs and perceptions. These findings are congruent with Kleinman's theory that there is the biomedical EM and a psycho-social EM; and that the psycho-social EM is often more prevalent in the patient perception and management of disease/illness.

Three articles were found exploring the use of EMs and culture in the Haitian population. The first one reviewed the multicultural guidelines that serve as a foundation for providing care that is culturally congruent with the patient's beliefs, practices, and understanding of illness. The intent of the first article was to provide a means for understanding illness in Haitians living in America by describing: 1) etiology, presenting concerns, and treatment of illnesses among Haitians, and 2) an examination of one particular illness, *Séizisman* (Nicolas et al., 2006). Nicolas and colleagues discussed causes pertinent to understanding illnesses by Haitians as supernatural in origin or naturally occurring. Supernatural causes include curses that others bestowed upon them, offending or neglecting

Iwa (gods often associated with voodoo beliefs), and strained God-person relationships (Nicolas et al., 2006). Haitians describe natural causes of illnesses as those resulting from things such as cold, food, air, heat, etc.). Examples of natural illnesses include colds, fevers, and even obesity (Nicolas et al., 2006). According to Nicolas et.al (2006) treatment of illnesses in Haiti is typically includes consulting family members, spiritual healers, and folk medicine. Haitians are known to turn to main- stream health care providers as last resort.

The EM of *Séizisman,* which literally means “seized-up-ness”, is evident in the aforementioned article. Haitians believe the etiology of *Séizisman* to be the result of rage, anger, sadness, and in some rare cases, happiness (Nicolas et al., 2006). A person presenting with *Séizisman* is said to be in a state of temporary paralysis as result of the stress induced by the event. The person inflicted with this illness is often unresponsive and unaware of surroundings. He or she may weep continuously and refuse to eat or sleep. Haitians report that this condition can last anywhere from a few hours to a few days. Haitians describe the pathophysiology of *Séizisman* to be the “movement of the blood to the head” (Nicolas et al., 2006, p. 704). Symptoms of *Séizisman* include loss of vision, headache, and increased blood pressure which may lead to stroke, heart attack, and sudden death. Haitians report that effective treatment may include massage, herbal teas, coddling, and counseling from a spiritual healer. This illness helps to identify the importance of health care providers recognizing patients’ beliefs of what is causing symptoms and tailor treatment as needed.

The second article reviewed was specific to EM in Haiti and looked at voodoo as a possible obstacle for Haitians seeking psychiatric care. The goal of this ethnographic study was to explore the relationship between explanatory models and treatment-seeking behavior related to mental illness (Khoury et al., 2012). Participants included 32 males and 23 females. Data was collected in variety of methods: 31 semi-structured interviews, 10 focus groups, and 4 case studies. The results of the study found that there were differences in the perceptions of mental illness and treatment seeking behaviors among those in rural Haiti and those in more urban areas such as Port-au-Prince (Khoury et al., 2012). This is consistent with Kleinman's premise that suggests that EMs are in fact highly individual and dynamic as opposed to consistent within cultural groups (Young, 1982). This study debunked the myth that belief in voodoo is an obstacle for seeking mental health treatment in Haiti. Although belief in voodoo may guide their course of seeking treatment, it is really the infrastructure of health care in particular areas and available resources that ultimately impact the treatment-seeking behaviors, despite the "etiology" prescribed to the illness (Khoury et al., 2012). This finding will be important to keep in mind as EMs are explored with regard to hypertension and self-management in the rural Haitian population.

The third article reviewed explored hypertension and EMs among Haitian immigrants living in the Bahamas. This was also an ethnographic study examining the EM of *tansyion,* creole for high blood pressure. This descriptive ethnography explored *tansyion* using semi-structured interviews from a convenience sample of 98 participants between 18 and 65 years of age (Mazzeo,

2013). Topics covered the interviews included basic demographic information, migration, employment activities, symptoms of *tansyion,* causes of *tansyion,* and treatment of *tansyion.* Findings of the study indicated that many attributed the etiology of *tansyion* to be the result of "blood heating up and rising as a result of stress" (Mazzeo, 2013). Symptoms reported included headaches, numbness, 'heaviness in head or chest', itching, blisters, nose bleeds, and fainting (Mazzeo, 2013). Treatment modalities included drinking almond leaf tea, managing stress through prayer, diet, exercise, and medication. Haitians believe that consuming hot foods, coffee, and alcohol are contributors to *tansyion*. The study also revealed that herbal treatments are the norm for high blood pressure among Haitians and Haitian immigrants, as a result of the cost and availability of medications. Alternative forms of treatment for hypertension among the Haitian immigrants in the study included the consumption of cold foods, almond leaf, coconut, and breadfruit. Participants in the study expressed a preference for medications, as they believed medications to "cool and settle the blood" more quickly and effectively than herbal medications, but reported being unable to afford medications (Mazzeo, 2013). The use of EM among Haitians in the Bahamas led to understanding of how this population perceives the etiology of hypertension, the desired treatment modalities, and the various alternative treatment options believed to be useful with *tansyion.*

Kleinman's EM also served as the theoretical basis for examining hypertension in two additional qualitative studies reviewed. The first study used semi-structured interviews to elicit explanatory models of hypertension among

patients followed in a hospital-based primary care practice in Nigeria. The goal of the study was to determine the patients' beliefs surrounding the meaning, causes, symptoms, and treatment of hypertension in order to develop culturally appropriate treatment plans and educational interventions, specifically for developing countries (Taylor et al., 2012). After analysis of data, results of the study yielded a variety of insights into the social and cultural factors of the Nigerian hypertensive participants. Of particular interest to the PIs was the finding that while the participants reported knowledge of hypertension and the serious consequences of untreated hypertension, their response to recommendations for treatment was not always guided by this knowledge. Many reported that a high degree of outcome control was "in the hands of God "as opposed to the health care practitioner (Taylor et al., 2012). This study also illuminated the premise that individual's EMs are subject and personal constructs of their environment, culture, and interpretations. For this reason, Taylor et al. (2012) supports Kleinman's notion that EMs are modifiable with education, knowledge acquisition, and experiences over time (Taylor et al., 2012), furthermore emphasizing the need for patient-centered education that is culturally appropriate and based on the individual's perceptions and beliefs.

Lastly, EMs were explored in Filipino Americans (FAs) with hypertension using an exploratory, descriptive design utilizing focus groups. Twenty-seven participants from two ambulatory clinics in Los Angeles and San Diego were chosen for the focus groups. This study examined the perceived causes of HTN in this population, symptoms associated with hypertension, and treatment of

hypertension. Results indicated that among first-generation FAs, causes of hypertension were attributed more to the pathophysiology of hypertension and less to the psychosocial attributes of the disease (Dela Cruz & Galang, 2008). For example, participants identified that medication and lifestyle modifications were essential to management of the disease and that management of the illness was a lifelong process. Participants reported that decreased fat and salt intake, increased exercise, and stress management were essential to hypertension control, along with medications. Although these strategies were known to be effective, it is important to note that participants frequently cited cultural reasons for non-adherence to treatment recommendations as evidenced by continued intake of ethnic foods specific to Filipinos, which are high in fat and salt. Researchers recognized the limitations of this study to be a small sample size, bicultural participants, as well as participants currently being active in a medically based treatment plan. Nonetheless, the use of EMs in hypertension made this article worthy of review.

Using the above studies as a basis of knowledge of Kleinman's Explanatory Model, the beliefs about and meaning of hypertension in Haiti will be explored. This focused ethnography will elicit EMs used by Haitians living in Domond, Haiti in order to learn more about the assumptions of etiology, symptoms, pathophysiology, course of illness, and treatment outcomes in this specific population.

Purpose of this Study

There have been studies conducted in the United States examining hypertension care and control in vulnerable populations, which identify many of the same barriers of those in developing countries, including socioeconomic status, illness perception, access to healthcare, and availability of medications (Baptiste et al., 2018; Hill et al., 1999; Lewis, Schoenthaler, & Ogedegbe, 2012). Increased prevalence and lack of care and control of hypertension has also been associated with perceptions of illness and awareness of disease (Baptiste et al., 2018; Chen, Tsai, & Chou, 2011; Dennison et al., 2007; Lambert et al., 2006; Polsinelli et al., 2017). The literature indicates that patient perspectives of disease and cultural variations impact care and control of hypertension.

Despite the growing prevalence of hypertension in developing countries, no studies address how the beliefs about hypertension or the meaning of the diagnosis may influence care and control of the disease. The purpose of this study will be to describe the beliefs and meaning of hypertension in a select area of Haiti with particular attention to participant perceptions of hypertension, specific religious/cultural practices that impact treatment, and beliefs surrounding the treatment of hypertension.

CHAPTER III

Research Design and Methodology

In Support of Method

This study utilized a focused ethnographic methodology to describe the beliefs about and the meaning of hypertension in the Haitian population. An ethnographic study allowed the principal investigator (PI) to become immersed in the culture, thereby gaining familiarity with the language, sociocultural norms, traditions, religion, family structures and expressions of emotion. Hammersley and Atkinson (2007) suggest that ethnographic research requires the PI to become involved in the participants' daily lives for an extended period of time. The PI spent a total of five weeks in the field listening, observing, and asking questions in an effort to more fully understand the phenomenon being studied. Agar defines ethnography as a collaborative, participatory methodology in which the representation of the research findings is neither that of just the participants or just the PI (Lambert, Glacken, & McCarron, 2011).

Practiced by early anthropologists as a form of fieldwork, ethnography stands apart from other methodologies by its emphasis on culture and the revelation of what happens in that culture. Ethnography has been described by Wolcott (2008) as *"a way of looking"* and *"a way of seeing".* The term "looking" refers to the methods a researcher uses in the field to gather information about the phenomena of interest. "Seeing" refers to how the researcher describes what they have observed from their fieldwork. The purpose of traditional ethnography

is to, “describe what the people in some particular place or status ordinarily do, and the meanings ascribed to the doing, under ordinary or particular circumstances, presenting the description in a manner that draws attention to the regularities that implicate cultural process” (Wolcott, 2008, p. 73).

In ethnographic studies, researchers study a particular group or phenomenon in a naturalistic setting, using three data collection strategies: participant observation, interviews, and examination of relevant documents (Cruz & Higginbottom, 2013). Wolcott (2008) describes these strategies as experiencing, enquiring, and examining.

Experiencing refers to participant observation in naturally occurring settings. In some of the early work of anthropological ethnography, researchers stressed the importance of moving back and forth from involvement and detachment in the research process. Wolcott (2008) discusses the role of the PI as “non-participant participant observer”. By this he means, the PI is present with the participants, observing intently their surroundings, their actions, and their expressions; without directly interacting with them (Roberts, 2009). Firsthand observation of the participant’s daily routines, cultural practices, diets, social support systems, and environmental surroundings will provide rich data that will serve as a starting point and filter for which all other data collected is screened. Descriptive data from observation serves as the foundation of the research from which we can then analyze and interpret further data from other sources involving more direct participation such as interviews (Wolcott, 2008). Researcher observations provide the ‘*etic’*, which is the alternative perspective

that occurs when the PI attempts to make sense of what has been observed (Cruz & Higginbottom, 2013; Roberts, 2009; Roper & Shapira, 2000). Wolcott refers to etic and emic as the outsiders and the insiders. The emic view is the "insider's" view. The emic emphasizes differences important within a particular community. The etic view refers to differences for the investigator making intergroup comparisons based on concepts and theories from outside the culture. Wolcott notes that there are multiple insider views and multiple outsider views. He emphasizes that every view is "a way of seeing, not *the* way" (Wolcott, 2008, p. 144).

Enquiring is more of an active role. This technique involves asking questions and engaging in conversation with the participants for the purposes of gathering data. Wolcott identifies several strategies that can be used when "enquiring". Two strategies that were used in this study are *casual conversation* and *semi-structured interviews.* Casual conversation was vital in seeking everyday information that is not specifically elicited with a conversation. Wolcott (2008) emphasizes the importance of casual conversation in the everyday nature of fieldwork itself. Casual conversation affords the PI potential to discover information that may otherwise not be formally solicited.

Examining entails seeking out information and/or items that may have been left by others, formal or informal. These types of historical pieces of data may enrich the ethnography by supporting the current data obtained in the observations, casual conversations, and semi-structured interviews (Wolcott, 2008).

Focused Ethnography

One advantage of ethnography is the flexibility that is offered in this type of research. This flexibility allows the lived experiences of the participants to evolve in their natural setting. Other advantages identified by Wolcott (2008) include: 1) ethnography can be conducted by one individual; 2) ethnography can be carried out in almost any location; 3) the problem may be taken to the field or uncovered in the field; 4) the method relies essentially on a human observer to observe humans (no expensive equipment needed); 5) ethnography provides a rich database for further research; and 6) the method emphasizes working with people rather than treating them as objects.

Focused ethnography is a type of ethnography that allows the researcher to hone in on one particular area of interest in a specific population. Focused ethnography offers the following additional advantages: 1) it is problem-focused and content specific; 2) ethnography focuses on a discrete community; 3) it involves a limited number of participants; 4) it included episodic participant observation; and 5) it can be used in the development of healthcare services (Cruz & Higginbottom, 2013; LeCompte & Schensul, 1999). Because it is problem focused, the focused ethnography becomes more *time intensive* as opposed to *time extensive* and relies more heavily on specific data elicited from participant interviews as opposed to extensive participant observations (Cruz & Higginbottom, 2013). LeCompte and Schensul add that focused ethnography is particularly appropriate and possible when the ethnographer is already

somewhat familiar with the setting, culture, and population, as in this researcher's case.

Because little is known about hypertension treatment and control in the Haitian population, this focused ethnography will provide data that may potentially lead to improved treatment strategies through the description of beliefs about and the meaning of hypertension in this particular culture. This methodology was appropriate for this study because the focus was on one particular health condition in a discrete community that is familiar to the PI.

Overview of Methodology

Focused ethnography allowed this researcher the opportunity to interact with participants in a variety of settings such as clinics, church services and within their home settings. Data was collected through participant observations, individual semi-structured interviews, and casual conversations at different times of the day and on various days of the week over five weeks, divided into multiple trips. Each week period consisted of 5-6 working days. These five weeks, coupled with the PI's previous experience and relationship building in the specified community, allowed adequate time for this focused ethnographic study. Total data collection time, for this ethnographic study from start to finish was 8 months. Semi-structured interviews designed to elicit specific information about hypertension from the perspective of selected Haitians living within a small, rural region constituted the primary source of data for this study.

This study provided opportunity for the PI to inquire about hypertension as a health condition and learn about decisions to seek treatment and/ or follow

treatment regimen through observations and the use of the primary RA for interviewing. Interactions with the participants in their various community settings (homes, church, market, etc.) permitted rich observational experiences contributing data related to religious practices, social interactions, lifestyle habits, perceived causes of illness, and treatment practices.

The guiding questions for this study were:

1. How do rural Haitians perceive hypertension as a health condition?
2. How do rural Haitians decide when medical treatment is needed?
3. What do rural Haitians believe about treatment of hypertension?
4. How do rural Haitians perceive their ability to manage hypertension?

Description of Settings

This research inquiry took place in the country of Haiti, which is the poorest country in the Western hemisphere according to the World Health Organization. Specifically, the study focused on the residents living in the village of Domond, Haiti. Domond is located in the northern, central plateau of Haiti and situated on the bank of the Artibonite River. Domond is considered to a be rural area. This community was selected because of the relationships the PI has established with the community leaders and residents during previous medical mission trips since 2010. This community has a documented high rate of hypertension from the visiting teams that travel to Domond in January, March, and June of each year.

Sampling and Recruitment

Inclusion/Exclusion Criteria

Inclusion criteria for participants in this study included: 1) Haitian adults over the age of 18 years; 2) both male and non-pregnant females; 3) residents of the village of Domond, Haiti; and 4) approved by community leader. Participants also needed a documented BP >140/90 at clinic visit. Since participants were not being diagnosed with hypertension or being treated by the PI and given the fact that hypertension is so prevalent in this population, just one elevated reading >140/90 was used for inclusion criterion in this study. Participants were chosen by purposive sampling from those presenting to a community clinic hosted by a team of volunteer nurse practitioners and nurses. Exclusion criteria included: 1) <18 years of age;2) pregnant females; and 3) those not willing to commit to individual interviews. Providers at the clinic were provided a list of inclusion/exclusion criteria in order to assist with the identification of potential participants for the study.

Recruitment Process

Recruitment of participants was completed during a routine clinic conducted by nurse practitioners and nurses at Voice of Victory church in Domond, Haiti on a specified date that had been announced in Sunday services. The clinic was held at the Voice of Victory Church located in the center of the village and was open to all regardless of religious affiliation, age or reason for seeking care. Historically, approximately 400 patients per day attend these open clinics, with > 50% of those being adults. Purposive sampling was used to recruit

participants based on blood pressure readings and medical history obtained during visit, inclusion/exclusion criteria, and recommendations/approval from the community leader. From a cultural standpoint, it was important to verify with the community leader that the participant was able to participate in the study, was dependable, and was a respected member of the community. These characteristics were necessary for both community leader support of the study as well as for retention of participants. The community leader was present at the clinic at the time of recruitment to provide feedback to the PI as to whether the identified participant was recommended for participation. The PI was made aware of potential participants by the nurses conducting the clinic. The nurses were briefed on the inclusion/exclusion criteria prior to the start of the clinic. As the PI was informed of potential participants, the community leader was consulted for approval prior to inviting the potential participant to be enrolled in the study. All participants enrolled in the study were recruited on the same day at this clinic utilizing purposeful sampling method. Patton (1990), states that the logic and power in purposeful sampling lies in information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research such as hypertension in this study.

Those who met the inclusion criteria were asked by the health care provider at the conclusion of their visit (and after approval of the community leader) if they were interested in participating in a study about hypertension. Potential participants who were interested then met with the PI and RA (RA) to

discuss the study. All potential participants had completed their clinic visit and received all medications from their provider prior to speaking with the PI and RA. In an effort to ensure that the participant did not feel that their receipt of medications or supplies was dependent upon participation in the study, the PI was not involved in the treatment or recruitment of potential participants attending the clinic.

Sample Size

Final sample size for semi-structured interviews in this study was projected to be 15-20 participants. This number was chosen in attempt to ensure that the PI could obtain both depth and variation in the data obtained. Of the 156 patients over the age of 18 seen at the clinic on this date, 68 were identified as potential participants in the study based on blood pressure reading and age. Of these 68, eleven were excluded due to pregnancy. Participants were consented on a first-come, first-served manner until reaching 18. Of those meeting inclusion/exclusion criteria, other reasons for not being enrolled in the study included: 1) participant declining; 2) participant unable to complete interviews due to obligations; 3) participant not able to return to the area for interviews, and 4) community leader determining participant not a good fit for the study, for reasons unknown to this researcher.

The PI chose to maintain this initial recruitment number of n = 18 for the semi-structured interviews in order to not over-enroll in the study for cultural purposes. This researcher was concerned that if too many participants were recruited, that all would need to be interviewed regardless of when data

saturation was achieved. This population perceives experiences such as this to be an honor and if recruited but not interviewed, there is potential that the recruited individual would be offended. Because over-enrollment would result in additional unnecessary expenses and time, initial recruitment was limited. All eighteen participants were interviewed, however during interviews it was determined that three potential participants did not meet inclusion criteria therefore, the interview data were not analyzed. Wolcott (2008), purports that it is important to focus attention on a fewer number of participants in order to gain depth as opposed to further spending time among more participants. There is not one right answer for sample size needed therefore, the final number of participants interviewed will be dependent upon when saturation of data is obtained (Patton, 1990). Wolcott states, “modest increases in sample size do not accomplish an adequate basis for generalization, but they most certainly compromise the opportunity to report in depth” (Wolcott, 2008, p. 93). Data saturation was in fact achieved with the fifteen completed interviews and a second recruitment of participants was not needed.

Protection of Human Subjects

Before the study began, authorization from the Rutgers Biomedical Health Sciences eIRB was obtained and the study was conducted as indicated by approval. Because of the language barrier, a bilingual RA was utilized to interview all participants. In addition, a second RA was needed during data collection and analysis. The primary RA was a Haitian medical student with a working knowledge of hypertension who is fluent in both Creole and English and

had previous experience working on an ethnographic study for a doctoral student in anthropology. The second RA was also Haitian and chosen based on his previous experience working as a medical translator at the clinics in the community. The RAs were trained by the PI in the aspects of the study and expectations of roles, including how to conduct the interview, where to conduct the interview, how to save and transfer data securely, and all post interview procedures (Appendix A). The primary RA was responsible for conducting interviews in Creole. All audio files were downloaded upon completion of interview session to a password protected computer used only for the purposes of the study. The password was known only by the PI and both RAs and remained locked up with all other study data and supplies (journal, logs, and recorder) at the Louise Mulligan House. Each RA signed an agreement to keep all information obtained for the study confidential (Appendix B) and had completed CITI certification in accordance with the IRB at Rutgers, The State University of New Jersey prior to the initiation of the study

According to the Central Intelligence Agency (2010), approximately half of Haiti's population is illiterate (52.9%). For this reason, oral consent rather than written consent was obtained for each participant by the primary RA at the time of study enrollment. The primary RA read aloud an established consent script (Appendix C) to the participant. The participant was given the opportunity to direct any questions regarding the study to the principal investigator. Because the interviews were audio recorded, the consent for audio recording of interviews was read to participants at the time of enrollment and verified again at the first

interview (Appendix D). All participants gave their verbal consent for audio recording.

Information regarding how to contact the PI was explained at the time of enrollment. Participants received a card with the phone number of the PI and primary RA listed to be used if questions arose during the study. All consenting participants were assigned an identifying number for use in field notes, interviews, and final report in order to maintain confidentiality. Participants were free to withdraw from the study at any time. Participants were also offered the opportunity to confer with the community leader and/or family members prior to providing consent.

The primary RA interviewed all participants in order to maintain consistency of data collection. All audio files (on recorder and laptop), field notes and journal entries were identified with the assigned identification numbers. To ensure confidentiality, all participant files were kept in in the designated locked area of the Louise Mulligan House. The guest house has onsite security 24 hours per day. The PI and RAs were the only ones with access to stored data in Haiti, both by key and password as needed for laptop. Data that was transferred back to the United States was securely kept in the carry-on luggage of PI (to include data located on password protected laptop) and immediately secured in locked file drawer of PI's office in Virginia upon return. Audio files of translated interviews were emailed to the PI by the primary RA via an encrypted email (see Appendix A). The PI saved emailed audio files to password protected external drive kept in locked file in PI's office in Virginia. Once audio files were saved

securely to the external drive, emails were deleted by both researcher assistant and PI. Demographic data was placed into Microsoft excel on a password protected computer. The audio recordings of the semi-structured interviews were transcribed by the PI using InqScrib™ and saved onto password protected computer used for the study. De-identified transcripts were transferred into NVivo11™ software for analysis using same password protected computer. Computer files were backed up on external drive and locked in the PI's office. All paper documents and electronic files will be destroyed three years following completion of study. When published or presented, data collected from this study will be reported as group data and participants will not be identified. Data sources and collection procedures are described more fully below.

Data Source and Collection

Data was collected using the techniques previously described by Wolcott (2008): experiencing, enquiring, and examining until saturation has been achieved. The primary RA determined the best means of communication with the participant in order to set up the interview date, time, and location. In addition, the RA provided the participant with information on how to contact the PI and/or RA when needed. At completion of the interview, participants choose from a selection of small gifts deemed appropriate by the community leader to show appreciation for their participation in the study. Gifts included sunglasses, personal hygiene items, and flip flops. Data collection continued until saturation was achieved.

The RAs were compensated for their time and work at $35-$40 US dollars per day. A typical day of work in Haiti is 8 hours in length; unless arranged ahead of time, an individual who works less than eight hours is still paid at a full day's wage, as compensation for the individual "devoting" their full day to service. This rate of compensation ($35-$40/day) was based on recommendations from the area community leader and covered all services provided (interviews, review of data, securing and transferring of data, and PI translation services).

Demographics

Demographic information was collected from the participants on the initial visit to clinic once enrolled in the study. Information was obtained by the PI with the help of the RA using a demographic questionnaire in Creole (Appendix E). The information obtained was entered into a Microsoft excel spreadsheet by the PI for further for final analysis.

Semi-Structured Interviews

Three practice interviews were conducted by the PI and primary RA during a routine clinic day prior to beginning the participant interviews. The purpose of these practice interviews was for the PI to provide coaching and instruction to the RA in order to ensure rich data would be collected during interviews with participants. Information gathered in the practice interviews was not utilized in data analysis. Semi-structured interviews with enrolled participants were conducted on the grounds of the Louise Mulligan Guest house and at the Voice of Victory church, depending on the participant's preference. The semi-structured interviews used a variety of ethnographic interviewing elements

defined by James Spradley (Spradley, 1979). It is not uncommon for Haitians to come to “events” in pairs or groups. For the purposes of this study, participants were asked to come alone to the interviews in order to ensure privacy and to prevent others from interjecting opinions during the interview process.

Each interview began with asking the participant to have a seat followed by the standard greeting of, “Hi, how are you today?” Participants were reminded about the consent to audio tape before the recordings started. Once the recording had started, interviews began with open ended questions, allowing the interview to take shape as it progressed. Each interview took approximately one hour to complete. Interviews were designed to allow the participants to speak openly and at length about their perceptions of hypertension as an illness, medical and non-medical treatment regimens, and any cultural implications of hypertension that may exist.

The purpose of an interview is to gain an understanding of the ‘emic’ view or the perspectives of the phenomenon from the participants (Cruz & Higginbottom, 2013; Roberts, 2009; Roper & Shapira, 2000). In order to obtain the Haitian participant’s perspective and beliefs about hypertension, interviews were guided with a series of initial questions (Appendix F), which were subsequently tailored to the specific participant, based upon their responses. This permitted the interview to evolve as a conversation, leading to further questions as needed for clarification. Initial interview questions, labeled as “Grand Tour” questions (Spradley, 1979) on the interview guide, were designed to elicit conversations that would provide insight into health beliefs of

hypertension, beliefs about illness management, support systems, and available resources.

Participants were interviewed individually by the primary RA using the interview guide provided by the PI (Appendix F). The interview was conducted solely in Creole which allowed for uninterrupted flow of conversation. The PI was not present for the interviews in order to not be a distraction or cause a break in the interview process.

Interviews were conducted in three sets of 6 participants each. A set was defined as the interview, translation, transcription, and analysis. Following each set of interviews, the primary RA transferred the audio file from the recorder to the laptop using the "sound organizer" software provided by the PI. Once downloaded, the primary RA listened to the audio file located on the laptop and translated to English verbatim using the recorder to create an additional audio file. A second RA was utilized to compare the two files (one on laptop and one on recorder) for verification of accuracy in verbatim translation. The RAs conferred on any discrepancies in translation and made notes in the journal kept by primary RA as to the specific correction in translation. The journal note included participant number and identified segment number or time mark of audio where correction has been made. This information was provided to the PI at time audio file was transferred for review (see Appendix A). Once the English version of the interview had been verified for accuracy by the second RA, the audio file was named "Participant #__Final" and saved on the designated password protected laptop. Previous versions of the audio-taped interviews were deleted with the

exception of the original interview completed in Creole. Because this second review of translation for accuracy occurred with each interview, back translation was not needed for this focused ethnography.

After completion of the interviews including translation and verification of accuracy, the primary RA sent translated audio files via encrypted email to the PI for data analysis and review. The next set of participant interviews did not occur until the PI had completed an initial review. This review between sets of interviews allowed the PI the opportunity to assess the flow of the interview and richness of data obtained before moving onto the next set. The PI transcribed all audio files verbatim using InqScrib™ and uploaded into NVivo11™™ for further analysis. According to Patton (1990), having the PI complete the transcriptions allows for a more intense immersion and familiarity with the data obtained. This process also gave the PI an indication if additional participants were going to be needed beyond the initial recruitment. Once the review and initial analysis of first set of data was completed, the process repeated until saturation of data was obtained. A total of three sets were completed resulting in saturation among 15 participants.

Participant Observation and Field Notes

Pre-established relationships gave the PI the opportunity to observe participants in their home, in the community, and in religious settings. The PI remained immersed in the environment by residing in Domond during her trips to Haiti. The PI was accompanied in the community by the second RA as needed. Observation at the homes of participants focused on activities such as food

preparation and storage, sleeping quarters, number of persons living in home, and size of home. Observations in the community focused on population density, occupational opportunities, closest established healthcare facility, and availability of transportation. Observation in religious settings allowed for a greater understanding of spiritual practices.

Field notes from the observations were kept throughout the study. These field notes focused on the lifestyle of the adult Haitian to include descriptions of the environmental setting; the group dynamics within the setting; the activity of the participants and others in that particular setting; and participants' emotions, body language, dress, and daily routines. During visits and observations, casual conversation occurred between the PI, participants, and other members of their families and community group. These informal conversations yielded further insight into the daily life of Haitians. This rich data was used in conjunction with the semi-structured interviews during data analysis.

Documents

The PI listened to the stories of participants and when the opportunity arose, inquired about previous medication documents such as unfilled or filled prescriptions. There were not enough supporting documents discovered to include these in data analysis.

Reflexive Journal

The PI and primary RA each kept a reflective diary, during the entire research process. The PI's journal provides a reflection of how personal interests brought the researcher to study this particular phenomenon in Haiti and served

as a method for controlling unconscious bias, while documenting the raw perceptions of the PI regarding participants and data. The RA's journal included the dynamics of the interview setting (too loud, too busy, etc.), problems noted with recording and/or transferring data, and other pertinent information about the participants on the day of interview. In addition, discrepancies noted in translation by second RA and their corrections were recorded in this RA's reflective journal. The PI made daily entries in the journal while in Haiti collecting data and as needed during data analysis. The primary RA made entries as needed for each participant interview and or follow-up. The journals were kept in a composition notebook and participant confidentiality was maintained by only identifying the participant with their assigned number.

Data Analysis

In contrast to quantitative research, data analysis in ethnography does not take place following the completion of the data collection. Data analysis in ethnography occurs concurrently with data collection and involves a repeated process of analysis until patterns become apparent (Robinson, 2013). Field notes and interviews for this study were analyzed and compared continuously as they were collected in order to identify similarities, differences, and common themes related to hypertension. As stated earlier, five interviews were conducted at a time and then analyzed. The PI was continually and repeatedly engaged in identifying patterns occurring from participant to participant. During this process of analysis, the PI actively mapped the experiences of the participants and self in terms of what was heard, seen, or felt that led to a particular outcome or belief.

This mapping occurred using both NVivo11™ and by hand. This process of pattern analysis allowed the researcher to take large amounts of qualitative data and reduce it to identified consistencies and meanings (Patton, 1990). As the observations and interviews continued, the PI compared newly collected and previously collected data occurred in order to identify emerging themes and codes for data analysis. Themes and codes were dynamic and evolving throughout analysis. The analysis of transcribed interviews and field notes continued until saturation of data had been obtained. Coding occurred after several reviews of the audio files and transcriptions were completed.

Once all participant interviews were completed and the initial coding and analysis had been done on each interview, a step by step analysis procedure was then used for a comprehensive review of the data. First, a holistic reading of all field notes and interview data was completed. Second, transcriptions of interviews were reviewed comparing the emerging themes and codes identified in the initial data analysis phase. Revisions to themes and codes occurred multiple times during analysis until the PI felt comfortable that the data was organized in a manner to best represent the Haitian perspective of hypertension. The PI made additional memos/notes in her reflexive journal to document the decisions made regarding codes and themes as they evolved. Third, codes and themes were finalized based upon the memos in the field notes and interview notes from PI and primary RA. The final step of analysis included final schematic coding to support the identified themes.

Trustworthiness

According to Roberts (2009), to help ensure trustworthiness of research findings, “researchers must be able to illustrate their steps in data collection and in the data analysis process, to demonstrate that the findings are not based on personal opinion, but on a rigorous analytical process” (p. 294). Trustworthiness of this study was established by time intensity in the field, member checking, thick description, peer debriefing, audit trail, and reflexivity.

Time Intensity

Credibility of traditional ethnographies is enhanced with prolonged engagement (Lincoln & Guba, 1985). Prolonged engagement requires the PI to be in the field long enough to gain a full understanding of the phenomenon being studied. Sufficient time in the field is achieved when lack of new emerging data is evident (Houghton, Casey, Shaw, & Murphy, 2013). With focused ethnographies, credibility is determined by time intensity rather than time extensity (Cruz & Higginbottom, 2013). Because the research is focused on a specific topic and a specified target population, the amount of time spent in the field is less but the intensity on the subject remains. Furthermore, LeCompte & Schensul (1999) purport that focused ethnography is particularly appropriate when the ethnographer is already familiar with the population the setting. The PI of this study spent extensive time in the community over the past five years in a variety of roles, averaging three trips to the community per year. The PI assisted with the development of a clean water system, volunteered in the local schools, helped with the building of a guest house for various visiting clinicians and churches, and

conducted nurse managed clinics. Through such activities, the PI established relationships within the community, and was able to building a strong bond of trust that aided the research process.

In this study, data was collected intermittently in the field over a period of 8 months. The PI spent a minimum of five days/week for five weeks in Domond throughout the data collection period. The PI lived among the participants in their village, attended their community events, and was able to spend time individually with each participant during the in-country visits. Intensity was achieved through constant daily interactions with the participants in their environment on repeated short visits. Analysis of data between visits allowed for identification of problem areas needing further clarification or exploration on future visits. Subsequent visits gave the PI and/or RA the opportunity to address these identified areas thus adding to the rigor of the study. The five weeks were spent as follows:

Week 1: training of RAs and mock interviews

Week 2: first set of semi-structured interviews and raw analysis

Weeks 3 and 4: in-country observations and data analysis

Week 5: member checking

Member Checking

Member checking was utilized to confirm the accuracy of the data collected once initial analysis was completed. All participants were asked to meet with the PI. During this meeting, the PI, with the RA present, verbally presented what was learned about hypertension from the interviews. Participants were able

to discuss and confirm accuracy of the data from the interviews and observations. There were no conflicting impressions that required resolving.

Peer Debriefing

According to Lincoln and Guba (1985), peer debriefing entails having another researcher who is competent in qualitative research procedures review the raw data to confirm the main ideas that are emerging from the research. Peer debriefing was conducted initially in this study by a PhD prepared colleague with experience in qualitative research. An additional layer of review occurred with experienced researchers serving on the PI's dissertation committee. Regular review and discussion of the emerging themes evolved through phone conversations and review of documentation submitted. This expert review resulted in rich discussions and analysis of themes to answer the research questions guiding this study. At the conclusion of analysis, these experienced qualitative researchers were able confirm the congruency and accuracy of identified codes and themes, as well as the logical paths taken to arrive at these codes and themes.

Audit Trail

An extensive audit trail was kept throughout the study, as recommended by Lincoln and Guba (1985) in order to allow others to critique the validity of the research. The audit trail contains a detailed record of the decisions made throughout the study. The PI found this particularly helpful with an international study that occurred over several trips. The ability to revisit notes regarding decisions made and what went well and what did not go well was valuable with

each subsequent trip. The audit trail also contained excerpts from field notes and interviews. The rationale for decisions made along the way in terms of methodology and data analysis was recorded. The audit trail will be explained more fully in Chapter IV.

Thick Description

Geertz (1973) describes thick description as a detailed description about the process, the context, and the people of the research. Thick description allows the reader to evaluate the quality of the research, and provides a holistic view of the phenomenon being studied. Thick description enables the reader to decide if the information is transferrable to other contexts. Detailed accounts of setting, interpreted data, participants, and the process are included in data analysis. Thick description is most evident from patient-provider interactions and daily routines observed by this researcher while living in the community as recorded in the researcher's field notes. Please see results Chapter IV for evidence of thick description.

Reflexivity

This PI engaged in reflexivity continuously as the study evolved. Reflexivity refers to "making explicit and transparent the effect of the PI, methodology and tools of data collection on the process of the research and the research findings" (Cruz & Higginbottom, 2013, p. 42). The aim of reflexivity is to acknowledge the influence of values, beliefs, and ideologies of the PI in order to establish the validity of the phenomenon being studied. Reflexivity requires the PI to be self-aware of potential biases that they may bring to the study which may

affect data collection and analysis. Cruz & Higginbottom (2013) suggest that reflexivity is an essential requirement of all qualitative research. Reflexivity within this study is evidenced within the reflexive journal discussed earlier.

Summary

The beliefs about and meaning of hypertension in the Haitian population were explored using the method of focused ethnography. The elements inherent within a focused ethnography illustrate that this method is appropriate for this specific population and this specific phenomenon given the PI's background knowledge of the phenomenon and the established relationship with the community. This study was completed over a period of eight months. Time intensity was accomplished by living among the participants intermittently for five weeks, observing their daily life and conducting individual semi-structured interviews. The data captured in field notes and audio recordings from interviews aided in answering the guiding research questions of the study. Analysis of data for emerging themes was ongoing throughout data collection with a more intense analysis occurring after all data had been collected. Analysis was completed with coding by hand, documentation in NVivo11™, and rich discussions with peer researchers. The PI was immersed in the data as result of self-completion of all transcriptions from audio taped interviews. Methods used to enhance trustworthiness included: participant observation, detailed field notes and interviews, thick descriptions, peer debriefing, and member checking. An audit trail and reflexive journal were also maintained throughout the study. This methodology provided insight into the phenomenon of the perceptions of

hypertension contributing to the beliefs about and the meaning of hypertension in the adult Haitian population as well as provided information that may be transferable to other similar populations in Haiti.

CHAPTER IV

Context and Informants

Historical and Sociocultural Context of the Research

Hypertension is of growing concern in Haiti due to the associated co-morbidities and treatment challenges existing in this resource-poor country. Mortality data for Haiti indicates that the country has the highest reported stroke rates in North America and one of the highest reported stroke rates in the world. Stroke rate data for Haiti is reported to be 176 per 100,000 or 10.3% of deaths (World Life Expectancy, n.d.). Haitians and healthcare workers alike are becoming more aware of this chronic disease, as indicated in the limited but evolving research on hypertension in Haiti and other developing countries. This focused ethnographic study explored the meaning of and beliefs about hypertension among Haitian adults. The purpose of the study was to learn more about the Haitian perspective of the chronic disease to include causes, treatment, symptoms, support systems, and nutrition. Data collection was accomplished through semi-structured interviews as well as casual conversations and observations in the field. For this research, fifteen semi-structured interviews were used for data analysis in conjunction with field notes from a total of five individual week-long visits over eight months to Domond, Haiti. Data analysis occurred continuously throughout this time frame. This chapter will provide an introduction to the setting and the participants of this study. A description of the audit trail will provide insight into decisions made along the way by the PI.

Introduction to Domond, Haiti

Domond, Haiti is located in the mountainous central, northern plateau of Haiti. Approximately 800 residents live within a narrow 3-5 mile stretch of land. Domond sits along the Artibonite River, which provides a source for bathing, laundry, and fishing for the residents. Domond is approximately 65 miles north of Port-au-Prince, the capital of Haiti. Domond is about 15 miles from Mirebalais, home to the region's nearest clinics and newest Partners in Health hospital. Although not far from a healthcare facility by standards of developed countries, transportation in Domond is extremely limited. Only the most affluent community members own a personal vehicle, and there is no public transportation system between Mirebalais and Domond. The primary means of transportation for the residents of Domond is by foot, making this a 15-mile walk for access to healthcare.

Domond is home to a government-run elementary school (K-8) and a privately owned elementary (K-8) school by the Patricia Sullivan Haitian Outreach Foundation located in Richmond, Virginia. Students wishing to pursue education beyond the 8th grade must find transportation and money to cover tuition at the "high school" in Mirebalais. There is one Protestant church and one Catholic church in the village as well as two known voodoo priests. Practicing voodoo priests can be identified by a white flag flying on the roofs of their homes.

Domond does not have a "grocery store" however, there is a weekly market where residents can buy and sell food, household supplies, and various medications. There is a clean water facility located in the center of the village

where residents can get water for cooking and drinking. Internet and cellular service are available; however, the reception is intermittent. Residents of Domond have access to electricity, although also intermittent, with average daily outages of approximately 8 hours per day. Residents of Domond are predominantly farmers and make a living by selling and trading goods and services. The average weekly income of residents varies from zero to five dollars. Some "work" to exchange products and services, making it difficult to ascertain the average weekly income of many residents.

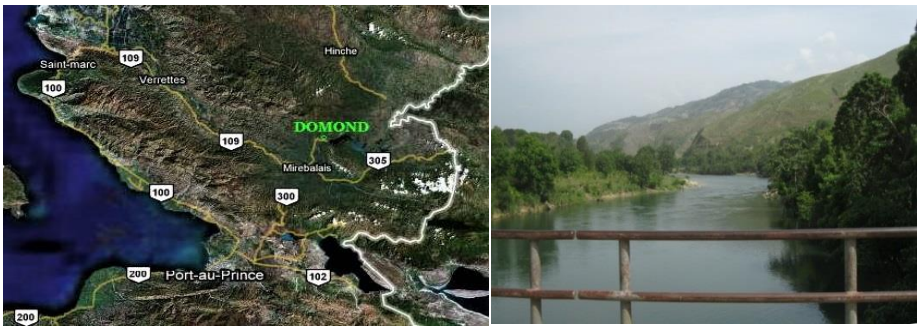

Figure 4.1. Map of Central Plateau and Artibonite River in Domond – photo from: https://lenouvelliste.com/public/article/139916/better-management-of-water-in-the-artibonite-basin

Introduction to the Participants

Fifteen of the eighteen participants who completed semi-structured interviews with the primary RA are included in this study. In addition to semi-structured interviews, the PI and participants spent time in the community together at church, at the market, in homes, etc. over the eight months. Eleven of the participants were female (73%); males were more difficult to recruit due to being in the fields during daylight hours. Thirteen of the fifteen participants were

between the ages of 41 and 70 years old, with nine of those between 41 and 60 years of age (Table 4.1).

Table 4.1

Participant Age and Gender

Demographic	***n***	**%**
Gender		
Male	4	26.67%
Female	11	73.33%
Age		
<40years	1	6.67%
41-50 years	4	26.67%
51-60 years	5	33.33%
61-70 years	4	26.67%
>70 years	1	6.67%

**Note.* Participants *N* = 15.

Fourteen participants (93%) reported having been previously diagnosed with hypertension before the recruitment day at the clinic, with 53% stating that they were currently taking medication for their hypertension (Table 4.2). Of the eight participants reporting current medication treatment, seven said their medication was aspirin (ASA). One participant showed empty bags labeled Hydrochlorothiazide (HCTZ) and Lisinopril and stated they had been out for about one week. At the time of enrollment, the mean systolic blood pressure was 167, and the mean diastolic was 102 (Table 4.3). The majority of the participants

did not hold a regular job, which is consistent with the number of females fulfilling the traditional role of managing the house while the husband works. Of the four working participants, one male participant held a formal community position in Domond, while two males and one female reported farming as an occupation. Fourteen of the fifteen reported living in a house (one room) with an average of six additional family members. Sixty percent reported eating two meals per day prepared over a charcoal fire. None of the participants reported smoking or drinking alcohol.

Table 4.2

History of Hypertension

Item	***n***	**%**
Previous Diagnosis		
Yes	14	93.33%
No	1	6.67%
Previous Medications for HTN?		
Yes	11	73.33%
No	4	26.67%
Currently Taking Medications for HTN?		
Yes	8	53.33%
No	7	46.67%

**Note.* Participants *N* = 15.

Table 4.3

Vital Signs

Vital Signs	***Mean*(*SD*)**	**Range**
Systolic	167.2(18)	140-200
Diastolic	102.9(11)	90-140
Heart Rate	89.6(8)	80-110
Height	61.2(3)	54-68
Weight	149.2(28)	102-220
Pain Level	5(2)	0-8

**Note.* Participants *N* = 15.

Description of the Audit Trail

It can be challenging to conduct a research study in another country where English is not the primary language. In particular, the PI needs to be flexible about decision making during data collection. The audit trail served as a valuable tool in guiding and detailing decisions made along the way. Field notes and the reflexive journal of the PI served as a resource for documenting methodological choices and challenges faced in the data collection and analysis phases of the study. While collecting the data, the PI quickly learned that documents and relics relevant to the study were non-existent and therefore, not included in data analysis.

Practice Interviews

During the interview training session with the RA, the PI decided that 2-3 practice interviews were necessary to aid in the obtainment of quality data. Practice interviews allowed the PI to determine if the RA understood the training and to make suggestions to support the flow of questioning. These practice interviews were conducted during routine clinic visits with patients who were willing to answer additional questions. The information obtained in the practice interviews was not utilized in data analysis. Following the practice interviews, a review of the audio and translations indicated that the RA did not fully understand the intent of some of the questions. In addition, the RA would tend to ask questions in a manner that would lead the participant to answer in a certain way. One example of this was the rewording of the following statement: "Tell me what role your faith plays in making decisions regarding your health." Instead, the RA changed the wording. "Tell me what role your Christian faith plays in your health. Do you go to church? Do you pray about it?"

Another opportunity for improvement discovered during practice interviews was the use of follow up questions to get the participant to elaborate on the answer given. For example, when answering a question regarding what is done to help lower blood pressure, the mock participant responded, "I boil leaves." The RA moved to the next item without inquiring what kind of leaf was boiled or why it was boiled. The opportunity to evaluate the interview technique before actual participant interviews proved to be valuable to the overall process.

As a result of the practice interviews, the PI made the decision to be present in the country during the first set of study interviews. The PI was not present at the site of the official interviews but was available to review audiotapes immediately following their completion. This immediate review allowed the PI to ask questions and seek clarification. Again, this added time and an additional trip to the study but proved to be valuable and allowed for increased PI immersion in the community.

Reviewing the Interview Data

A second RA was utilized to verify the translation of interviews for accuracy before the PI completed transcriptions. Coding was done by hand on printed transcripts in sets of six, as interviews were completed and transcribed. The PI consulted with a Ph.D prepared colleague for comparison and discussion of codes with each set, as well as another clinician who has done extensive medical work in Haiti. Discovery of emerging themes and patterns occurred with the second set of interviews. The PI met with colleagues to review data after the third set, interviews 12-18, and concluded that reoccurring themes in the data were evident. Eighteen interviews were completed and transcribed prior to coding. Three of the eighteen interviews were not utilized because the PI could not verify that the participant had fully met all inclusion criteria. One participant was pregnant, and two did not have a BP >140/90 on recheck at time of interview.

Following all interviews and hand coding, the PI then completed an additional comprehensive read and review of transcripts and field notes. The

transcripts were read multiple times and compared with field notes. Once validated for accuracy, the transcripts were transferred into a computer for use in NVivo11™ software for an additional layer of analysis and coding exploration. Phone conferences were held with committee members who had expertise in qualitative research in order to discuss the emerging themes and possible meanings. The phone conferences added an extra layer of review and discussion leading to the further refinement of themes and conceptual schema.

A final trip to Haiti was made by the PI eight months after the start of the interview process to meet with participants to present the findings and to complete member checking. The participants were offered the option of meeting individually or as a group at the Voice of Victory church. All participants chose to meet together to hear the findings. Many reported, "feeling honored to be included in the celebration." Results were shared with the participants using the coding categories. The PI cited examples from the data with the assistance of the RA serving as translator. Twelve of fifteen participants attended the session, and all agreed that the data captured is accurate. After member checking, participants expressed a desire to continue to be followed for their "illness" and thanked the PI for spending the time in the community. Follow up care and monitoring was arranged with the medical teams of the Patricia Sullivan Haitian Outreach Foundation.

Methodological triangulation occurred by comparing the transcripts from interviews and field notes for emerging themes. Data analysis was completed comparing the transcripts and field notes side by side and discovering the

congruency between what was said and what was seen. This constant comparison back and forth among all documents (transcripts, reflexive journal, and field notes) provided opportunities to highlight examples with thick descriptions from interviews, visits in the homes, walks through the community, church services, and market days to name a few.

Summary

Data for this focused ethnography study was collected through semi-structured interviews and field notes. This chapter provided a description of the community setting and the participants from which the data was collected. Details from the audit trail were shared to highlight decisions made in methodology to enhance the data collected. The PI was heavily engaged in the interview process, although not present for the actual interviews. Fifteen interviews were utilized in conjunction with field notes for the identification of patterns and themes.

CHAPTER V

Description and Discussion of Themes

This focused ethnographic research explored the Haitian adult's perception of hypertension. The research questions guiding this study helped to provide answers to the overarching research question regarding the meaning of and beliefs about hypertension of a Haitian adult. These questions were:

1. How do rural Haitians perceive hypertension as a health condition?
2. How do rural Haitians decide when medical treatment is needed?
3. What do rural Haitians believe about the treatment of hypertension?
4. How do rural Haitians perceive their ability to manage hypertension?

Through the exploration of these questions related to hypertension, themes emerged regarding the feelings associated with hypertension as well as management and cultural influences impacting treatment and outcomes. Data was collected for this research study through individual interviews with fifteen participants, field observations, and the PI's reflexive journal.

There was an overarching theme of hypertension as 'a feeling' one gets that requires immediate attention and relief. Without relief, the possibility of "falling down" is a genuine concern and fear of this population. The goal is to obtain fast and immediate relief from the presenting feeling to prevent "falling down." It was not uncommon for the researcher to be approached at the market and led to someone with contractures or other post-residual stroke manifestations. Participants described in detail the possibility of falling and

becoming numb and possibly dying as a result of high blood pressure. While listening to the stories such as this, this researcher was reminded of the condition known as "s*éizisman*" in Haiti which is the “movement of the blood to the head” (Nicolas et al., 2006, p. 704) causing one to become motionless as discussed previously in Chapter II.

Comprehensive analysis of the data revealed sub-themes related to the overarching theme and goal. The first theme revealed that distinct factors are contributing to the feeling/s that one experiences associated with hypertension. The second sub-theme occurring is related to the management of the feeling. This sub-theme is more complex and divided into categories of short-term, long-term, and spiritual strategies utilized to manage the feeling. The data in this study highlighted the complexity of the perception of hypertension in the Haitian adult population. This complex perception contributes to the challenges associated with the management of hypertension in the Haitian population, thereby helping to explain the WHO data indicating a growing rate of heart disease and increased mortality rates in Haiti. An in-depth exploration of the contributing factors and management practices assisted with the understanding of the Haitian EM of hypertension. Haitians act as the result of a presenting feeling. The ultimate goal of the actions taken is to prevent falling, which is associated with numbness and possibly death. Recognizing the contributing factors and the ability to manage those contributing factors are essential key components of how this population perceives hypertension, as illustrated in Figure 5.1.

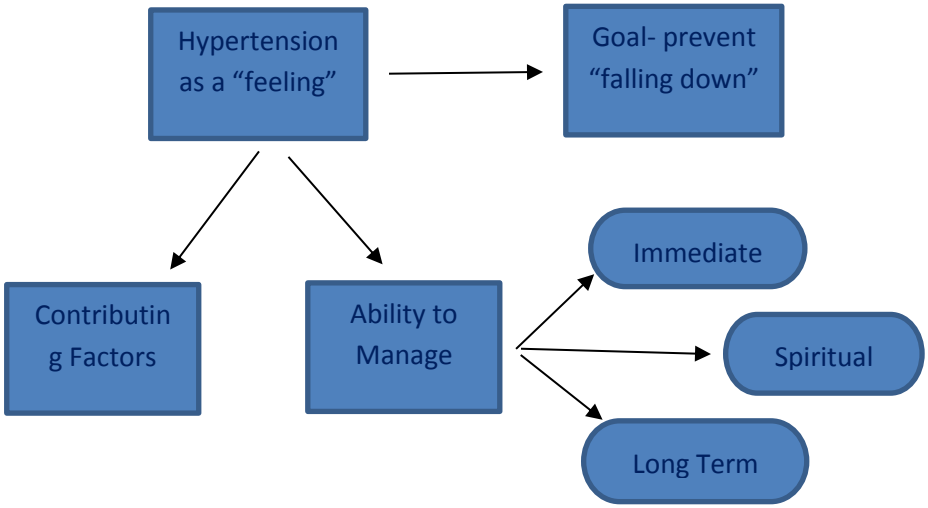

Figure 5.1. Understanding perceptions of hypertension in Haitian adults.

HTN is a Feeling

It seems natural that physiological symptoms would be the overarching theme when exploring the perception of hypertension among any population. Exploration of why one thinks they have hypertension in this population consistently led to a description of physiological symptoms, or *that* feeling one gets when their tansyion is gro (pressure is high). In a population such as the one involved in this study, it is these feelings that often lead to self-diagnosis and treatment in resource-limited communities. Hypertension is "my head hurts," "my eyes are blurry," "I feel burning" or "I am dizzy." Hypertension is also associated with feelings of anxiousness, anger, and being upset. When discussing these feelings of hypertension, participants would relate the progression of untreated feelings to becoming numb and then falling. There was a sense of urgency to get relief from the presenting feeling to avoid falling, which has a more significant

connotation of long-term detrimental health impacts. The fear of these harmful health impacts will be discussed more fully later in this chapter.

One participant told the story of feeling the “burning pain and hot feet” after working in the fields all day. She states, “Sometimes when I am walking, and I feel like under my foot, it is so hot even when I am crossing the river. I put my feet in the water, and it is still hot. At this time, I feel like I know that it is the high blood pressure. My heart is starting to beat very fast.” The physical feeling of "hot" or "blood boiling" is common among Haitians. It is hard to discern if the hotness is related to actual heat and humidity or a symptom of something pathologically raising the blood pressure. To complicate this further, some Haitians define "makes my blood boil" as a term referring to being angry or upset. Anger and being upset is also associated with causing high blood pressure resulting in severe headaches and being tense (Table 5.2).

During the interviews, each participant was asked, "Why do you think you have high blood pressure? What causes it?" The typical answer was to respond by describing the feelings they were experiencing. In some cases, the participant responded by informing the interviewer that they went to see a doctor once and were told the feeling such as a headache, was high blood pressure. The most common feelings described in the interviews included headaches, blurred vision, and dizziness. These symptoms are congruent with symptoms of uncontrolled hypertension in developed countries such as the United States. Pounding headaches with stiff necks and blurry vision were described by 10 of 15 participants. Other feelings commonly expressed were generalized stiffness,

numbness, and "breathlessness." When describing feelings associated with high blood pressure, once again, the urgency to relieve the symptoms was emphasized as necessary to prevent "fatal" consequences and "falling down." The table below depicts the frequency of identified feelings appearing in the interview transcripts when asked the question, "Why do you think you have high blood pressure"? During the conversations, headaches were by far the most frequently mentioned feeling of hypertension. Numbness, weakness, and falling were often mentioned; however, these particular feelings were discussed as feelings to come if blood pressure continues to be high. These feelings will be explored more in-depth later in this chapter with the discussion of the concept of falling down.

Table 5.1

Feelings Associated with Hypertension

Symptom	**# of times referenced**	**# of Participants that Mention**
Headache	34	11
Numb (Numbness)	22	8
Burning/Hot	16	11
Falling	11	11
Blurry Vision	11	11
Dizzy (Dizziness)	10	10
Stiff (stiffness)	6	4
Breathless	5	5

**Note.* Participants *N* = 15.

Contributing Factors related to HTN

The overarching theme of “a feeling” is supported by sub-themes related to factors contributing to the development of the feeling. The semi-structured interviews included questions that revealed environmental influences, cultural influences, and behaviors which cause feelings associated with hypertension to occur. These contributing factors help to explain the Haitian adult's understanding of hypertension. As stories evolved, participants commonly discussed climate, physical labor, home life, noise, anger, and diet (or lack of) as reasons for why they get high blood pressure. There was a significant emphasis on stress, both physical and mental. It is important to note that when discussing the contributing factors, participants would start by saying, "when I *get* high blood pressure." This phrase suggests that hypertension is similar to a passing illness (comes and goes) as opposed to a chronic disease that one lives with daily.

An analysis of the data related to contributing factors was completed using field notes, observations, and semi-structured interviews. Quotes and stories from interviews provide insights into the beliefs surrounding possible causes of hypertension among this population. This researcher grouped these factors together as ultimately contributing to the reasons perceived for experiencing the feelings discussed above as hypertension. It is essential to understand the perceived causes of the feelings to understand the management practices that also emerged in the data. Participants were asked, "What do you think causes high blood pressure"? Overwhelmingly the answer to this question was either related to diet or stressful situations however, three participants implied that

some Haitians get high blood pressure as a result of "doing bad" or as a result of a "spell."

Climate, Physical Stress, and Emotional Stress

The idea of both physical and emotional stress predominated in the interviews as causing blood pressure to rise. Daily life in Haiti was depicted as both physically and emotionally taxing during the interviews. Field notes of the PI describe interactions, conversations, and observations also highlighting the everyday challenges of the Haitian adult. Interviewees describe sources of tension related to physical heat, physical closeness to others, manual labor, and dependency on others for food and basic needs. Data reveals it is believed if one can eliminate the source of stress occurring at that moment, high blood pressure will go away. Some feel they are able to manage the growing tension and others feel that situations of stress are out of their hands.

One afternoon while walking to the river, an elderly woman asked the PI for something to eat. With the translator nearby, the PI learned that she was one of the widows in the community. She explained to the PI that she was alone and had no food for the day as her family had traveled to Port-au-Prince and would be back later. She told the PI that she worries without food she will get sick and fall down but she has no choice. Similar stories were shared in the interviews highlighting the association between limited resources and hypertension. Table 5.2 provides samples of physical and emotional stressors as described by the participants. The causes associated with increasing hypertension will be

discussed more in depth later in this chapter when discussing the Haitian adult's perception of their ability to manage hypertension.

Table 5.2

Climate, Physical Stress, and Emotional Stress

Causes of HTN	**Participant**	**Evidential Participant Quote**
Climate	7	I start having this when I am getting old and doing too much like walking in the sun.
Climate	13	I think it is because of too much exposure to the sun too.
Physical Stress/Heat	4	Mostly b/c I am a woman working in the garden as a farmer selling stuff. I have no other jobs. Sometimes when I am walking, and I feel like under my foot, it is so hot even when I am crossing the river. I put my feet in the water, and it is still hot. At this time, I feel like I know that it is the high blood pressure.
Physical Stress/Heat	14	It is because my belly always hurts and dizziness. I used to cook and sell food, but now I can't do it anymore. Because people think that if I stay cooking the heat will make it worse. So I stopped cooking, and now I am doing nothing. I do not even have food.

Emotional Stress	1	Sometimes if I get upset, I don't talk, but I get upset, that it could get it high.
Emotional Stress	2	They [family members] know it, and they also have high blood pressure. They advise me don't talk too much, don't get upset so that the high blood pressure won't make me numb.
Emotional Stress	3	Yes, when I am getting upset, the blood pressure is getting high.
Emotional Stress	7	If you are yelling or getting upset with someone, talking loudly, it could be higher. If you aren't doing things right, it can be higher.
Emotional Stress	10	But for this case, you can see that in my job there are so many stressors and we don't get paid well. And so many things go wrong, frustration and bad news. Compile all of them together that makes it become worse.
Emotional Stress	11	This could go higher and become limitless because it is all everything that is mixed together even on the news we listen to, economic situations, and all that together makes it get high.

Emotional Stress	12	Sometimes the kids make me upset all the time. Talking too much and makes it higher.

Voodoo/Spiritual Associations

While not openly discussed among the participants in interviews, the PI noted intriguing details within the interviews relating hypertension to a spiritual cause. Three of the fifteen participants mentioned voodoo within their interviews. The first participant was a 51-year-old male. When asked about the cause of high blood pressure, he replied: “When you don't feel better, some of your family members think that it may be something like from the devil. Some kind of spirit that hits you somehow but you don't really see it. And something that you have to cross over a line on the floor. When you step on it, it makes you feel bad." This particular participant mentioned this spirit and line on the floor twice during his interview as a potential cause for high blood pressure. Another female participant shared that if doing something wrong, this could result in a curse placed on you. The curse can cause illness that can lead to you to falling down and possibly dying. The voodoo priest causes this curse and can also eliminate the curse if desired. During her interview, she indicated that voodoo curses are not the cause of her high blood pressure; however, she is aware of others who believe curses are the cause. The PI discussed voodoo beliefs and practices with the RA to learn more about the data from interviews. The RA commented that often people reference voodoo as something someone else does but, in reality, they are speaking of themselves. The RA explained that more than likely the participants

were referring to themselves but for fear of judgement, disguised their comments as experiences of someone else.

When reviewing the interviews, the PI asked the two RAs about their thoughts on the prevalence of voodoo in the community. Both quickly indicated voodoo is "bad" but believe many in the community utilize priests when unable to find relief. The RAs clarified that they do not agree with the idea that a curse or a spirit can cause the pressure to be high. Voodoo will be discussed again later within this chapter when talking about the Haitian's perception regarding their ability to manage the feelings associated with high blood pressure.

Dietary Factors

Participants in the study were well educated on dietary practices impacting high blood pressure. As in most countries, food has cultural implications. In Haiti, there are certain foods, spices, and beverages that are staples in the everyday diet, which negatively impact blood pressure. Furthermore, meats are often deep-fried in oil over charcoal fires, as traditional kitchens are a rare find in rural areas of Haiti.

Maggi. Maggi is a spice frequently used in Haiti for meal prep. Haitians associate the "bon gou” (great taste) of food with maggi and lots of it! Maggi is comparable with a bouillon cube comprised of sodium, hydrogenated fats, and monosodium glutamate (MSG). Just about everything that is cooked in Haiti uses maggi in abundance per the participants in the study. “If no maggi, then my family won't eat it because it does not taste good," said one participant. Another reported cutting back on the maggi but still using it so her kids would eat their

food. When observing meal preparation on several occasions in Haiti, the PI commonly saw as many as fifteen maggi cubes placed in a pan of boiling water with vegetables such as potatoes and carrots. Careful not to offend, the researcher asked if there was something that could be used in place of maggi to improve the taste and be healthier. The women cooking laughed and replied, “You will need garlic, rosemary, leeks, dill, parsley, and other things to do that. That is too much to find and gather. Too expensive.”

Although careful not to eat food prepared on the ‘street' for fear of stomach upset, this researcher did eat meals prepared in the guest house. Meals at the guest house were made on a gas stove by a local Haitian cook. Vegetables were boiled with approximately six cubes of maggi (due to the PI requesting less be used), and meats were fried with oil on the stovetop. Despite asking for less salt and maggi in prepared foods, within 48 hours of arrival, this researcher had edematous hands and feet from salt retention.

Coffee. Another dietary staple in Haiti is coffee. Coffee beans are grown in abundance in Haiti and therefore provide an easily accessible and very affordable beverage option. Homegrown and hand ground, the coffee is rich, dark, and flavorful. Coffee prepared at the guest house was freshly ground, thick, and black as midnight. Coffee was available from 4 am until bedtime as a beverage of choice. One study participant reported drinking 10-12 cups per day, while others said about half that amount as the norm. "Tansyion gro, pa coffee” followed by laughter was often heard when out observing and interacting with the residents of Domond. “Pressure high, no coffee” was what they were saying.

While there is no evidence linking coffee consumption to high blood pressure, Haitians believe this to be a cause.

Throughout the interviews, participants expressed a desire to eat healthier and modify their diet to lower blood pressure by eating less fried foods and less salt. One participant noted that this was hard to do stating, "If you are not the cook, you eat what others cook if you are hungry. You don't complain." Depending on family dynamics, cooking is often an assigned task in which one person cooks for several extended family members, while others are farming or at the market. It was clear that one eats and drinks what one has access to, particularly when choices are minimal. Challenges associated with meal prep led into the discussion of the perceived ability of Haitians to manage hypertension.

Ability to Manage

The contributing factors discussed above are referred to as “modifiable risk factors” according to the American Heart Association (American Heart Association, n.d.). However, in Haiti, the ability to modify risk factors appears to be much more complex, and yet at the same time, very simplistic. Management of the factors contributing to the feelings associated with hypertension consist of short-term (immediate relief) strategies, long term strategies, and spiritual strategies. The priority is obtaining immediate relief. Self-care practices that are perceived to provide this immediate relief proved to be insightful when examining the meaning of and beliefs about hypertension in the Haitian adult population within this study. How one treats feelings associated with what they believe to be the source of high blood pressure, as well as the outcomes achieved with such

treatments, helps to explain perceptions of the disease. Management practices are directly related to the resources on hand when the feeling is present. Developing countries, such as Haiti, lack access to healthcare and regulated medication resources. This lack of resources results in dietary, homeopathic, and stress relief practices. Despite interview data indicating that all fifteen participants believe medication was the best option for managing high blood pressure; the one reporting regularly taking medication added, “unless it is all gone. Then I wait until I can get some more."

Short-term/Immediate Relief Strategies

Almond leaves. Almond leaves were mentioned by over half of the participants as the therapeutic method of lowering blood pressure when unable to get medications even though there is no current evidence to support this belief. Almond leaves are boiled and then used in a variety of ways as a self-care technique to lower blood pressure. Haitians typically drink the tea made from boiling the leaves; however, some report placing leaves on their forehead or the bottom of their foot when they feel their pressure rising. One participant explained, "I used to take some almond leaves and make them as a tea and drink them. If I don't have them, I used to take papaya. They tell me it is good and I use it and find a solution. You eat it (the leaves), or you drink the water. It is good for high blood pressure". There was a strong consensus among participants that this is a proven method to get blood pressure down. Another participant reported placing the soaked leaves on the balls of their feet to lower the pressure as opposed to drinking the tea. Placing the leaves directly on the feet is believed

to reduce the "heat in the blood" to provide faster relief. As a practicing nurse in Haiti, this researcher has seen similar methods with medications typically ingested. For example, while in the community, this researcher was called upon to look at a leg wound. The older man had been given an antibiotic for the infection. Instead of ingesting the medication, the man crushed the pill and packed it into his wound, creating a paste at the wound site to achieve immediate relief.

Relieving sources of stress. Other strategies utilized to lower blood pressure quickly focused on alleviating the presence of stress. The presence of stress in a resource-limited population is a common occurrence. During the interviews, participants explained self-care techniques to remove themselves from stressful situations. Arguing, loud talking, and being upset increases or causes their blood pressure to go higher according to participants in this study. Physical labor associated with routine daily tasks is also a source of stress.

Field notes and observations depict an environment in the rural countryside in which "homes," inches from the road, are subject to motorbikes blowing their horns every few seconds, loud music playing, babies are crying, and people are talking loudly in the streets to be heard. This hustle and bustle begins around 4 am and continues into the night time. Finding a place to relax and be quiet is not an easy task in Haiti, even in rural areas. Daily life in Haiti is hard work. Routines consist of getting up with the chickens, literally, followed by preparing for the day's activities. Men report to the fields, and women begin food

prep for the day or go to the market to sell goods. Children take care of children. Women commence with food prep, laundry, or selling at the market.

This researcher had the experience of spending the day with one participant as she made meals for a feast to celebrate Palm Sunday. Preparation consisted of observing both chickens and goats being slaughtered and then prepared for cooking. The process took approximately 4 hours to complete. The manual and physical labor associated with food preparation is taxing and yet routine at the same time. Following the laborious meal prep, hand washing of laundry at the river bank follows. The laundry is carried in a large bin on top of the head to the river. All garments are then soaked in the water and hand scrubbed vigorously. The women would laugh as this researcher's arms grew tired and weak from scrubbing. Once washed, heavy, wet garments were placed back into the bucket and carried up to the house to dry in the sun.

The days are long and end with the family often going to bed with 3-4 persons per small bed or on the dirt floor with a grass mat. Privacy is limited, thus playing a role in rising tension and arguments as days progress. Participants describe becoming upset at times, increasing their blood pressure. Methods reported to lower blood pressure when feeling stressed or worried include lying down, being quiet, no talking, and staying in the corner. Participants believe these strategies help to reduce blood pressure. Allowing oneself to calm down and cool down emerged as the ideal treatment method for lowering blood pressure.

Cooling off. The ability to manage the feeling of being hot, burning, or blood boiling was discussed often in the participant interviews. Stories described the self-care practice to lower blood pressure as taking cold showers or pouring cold water over one's head. A frequently mentioned method to cool down includes removing all clothing. Table 5.3 below provides a summary of quotes detailing how twelve participants spoke about the use of cold water to help obtain relief for high blood pressure.

Table 5.3

Cold Water Treatment

Participant	Evidential Quote
1	I go under the water pipe, and I refresh myself, and I shower and shower and shower. I just take off all my clothes. And after if I find a place where it is calm and cool, and I just lay down. If not, I call someone to help.
1	I eat. I take rest. If the high blood pressure is too high while I am working, I just stay in the corner and wait until I feel better to get up. Or, I pour some freshwater on my head to refresh me.
2	If I have medication, I always take them and take a shower and pour water on my head and don't eat salty food.
3	Water. I pour water on me.
4	Yes, I used to take a shower and pour water on my head. Take off all my clothes.

6	I have to lay down and pour water on my head and stay on the ground, and that is all.
8	You pour water on your head, but no one that comes to help you should grab you. I just sit and stay quiet, and I call someone close by my house to bring some water, and I pour it on my head.
9	I take a shower and shower. After that, I lay down and sleep, and when I get up, I feel better.
10	I take a shower, and by traditional behavior, we boil some tea. My wife boils some tea for me.
12	I pour water on my head and use the almond trees that I boil. I lay down. Later on, I can get up.
13	I feel like all my body become hot, moving my body too much and I get some water and pour on my head. I try to get somebody to pour water on my head. I lay down almost on the floor without nothing on my body.
14	Take a shower and wash with soap.
15	I am not too worried b/c every time that I feel that the high blood pressure is there I try to get some of my pills and cool down with water. I pour water on my head.

Management strategies discussed above are all things done to alleviate the feeling that one is experiencing in that moment. Treatment options are based on the resources at hand for what is perceived to be a quick relief mechanism for the reduction of the feeling associated with rising blood pressure. The next

section will discuss the long- term strategies utilized by Haitians in the treatment of high blood pressure. The brevity of the following section highlights the lack of long- term thinking related to hypertension.

Long-term Management Strategies

Interviews revealed that long-term strategies for the management of hypertension were mainly limited to dietary practices, although medication surfaced as the preferred treatment. Further exploration of the utilization of medication revealed that routine medication management is not a concept that appeared to be understood or practiced in this population. In addition, while dietary modifications were identified as the most well-known long-term solution, there were difficulties identified with maintaining such modifications long- term.

Medication management. When participants were asked if a medication was necessary to treat high blood pressure. 100% of the participants agreed that medicine is the most effective treatment, and if available, they would take a pill if given one. This researcher learned during home visits that the medication they were referring to is ASA. Further probing revealed that ASA is not taken daily for the treatment of high blood pressure but rather as needed. One participant showed a full bottle of ASA and commented that she saves it for when she "feels the pressure to be high." Another indicated that he was instructed to take the pill (ASA) when feeling bad so that he would not have a stroke. The PI clarified and asked if he takes the ASA every day so that he will not have a stroke. He laughed and replied, "Oh, no. I save them for when I feel it is high and then I take one." The one participant that reported taking medication "regularly" for his blood

pressure showed this researcher an empty clear, plastic bag labeled as Lisinopril. When asked if he had more (because the bag was empty), he replied, "I will need to wait until the man who sells this comes back to market next week to get more." These examples highlight the challenges with long-term medication management of hypertension as well as the regulation of authentic medications in this population.

Dietary modifications. While dietary modifications prevailed as a long-term strategy that participants discussed to combat high blood pressure, there were challenges with this strategy. The older participants indicated that they do not do the cooking, so they cannot control their diet all of the time, despite knowing it is necessary. Many stated they ask for less salt, less maggi, and less fried foods but must eat the food as prepared. The importance of fresh vegetables and salad was identified as a dietary preference when such resources are available. One participant shared that as a farmer, he has access to fruits and vegetables and keeps some for himself when able, but frequently, he sells them at the market for the money. Another participant stated, "Don't put maggi, pasta, tomato. It is better if the food does not taste as good as you like, because it will be healthy". Analysis of the data indicated that Haitians are aware of the implications of dietary choices and when able may attempt to control or modify choices.

Spiritual. Haiti is a country rich in faith and spiritual practices. Spiritual practices can be of Christian origin, voodoo origin, and commonly a combination of both. Voodoo is frowned upon by many, so getting participants to speak up

about it is more difficult to do. However, one participant in this study did mention voodoo priests as a source used for the treatment of high blood pressure. The participant emphasized that she did not believe this to be the method of successful treatment as, "only God can make a treatment" but stated many others do believe in this. When asked to elaborate on treatment modalities, she indicated that treatment by voodoo priests consists of injectable medications in the nose for the relief of high blood pressure. The participant was not sure of what is injected for this treatment option.

Regardless of type of spiritual practice, all participants felt that faith was instrumental in the management of hypertension. During interviews, when discussing the lack of resources, participants highlighted the importance of prayer and spiritual healing when lack of food and medication exists. Conversations regarding medications and food sources circled back to prayer and relying on God to find a solution and heal the feeling known as high blood pressure. Participants would often smile and nod their head in affirmation when speaking of the power of prayer and the importance of faith in situations that are out of their control. Table 5.4 provides examples of this.

Table 5.4

Spirituality and Faith

Participant	**Evidential Quote**
1	God will make you feel better.
2	I pray, and I pray for the high blood pressure

4	I don't have close family. When I have high blood pressure, I have to call on God and the doctors.
6	If you have faith, you think that you will feel better. But if you don't have faith, maybe you won't find the solution, and the disease could get worse.
7	I believe in God, and I always go to church. I am in the choir. I always come and pray. I think God can bring a solution.
8	With anything that you are doing that can turn wrong, if you pray to God, then everything could change. I believe that he can help me with my high blood pressure in the name of Jesus.
10	Mostly when the situation is really higher than I thought it is, I just pray. I am not too worried because I believe in God.
11	I know that one day, I will have to die, but I trust that I will stay with Christ.
12	I only come to church and serve God because it is God that can do everything. I hope to find a solution and that he will be healing me anyway.
13	Some people go and find some other people to give them some other medication like to put on their nose or like injectables. I don't think that is necessary because my father and mother did not teach me like this, so I don't use those

	kinds of things. Only God can make a treatment.
14	When I feel discouraged, I just come to God
15	Just stop and start to pray and find a solution.

Preventing “Falling Down”

Exploring how hypertension is perceived in the Haitian population led this researcher to the conclusion that the goal of recognizing the ‘feeling’ associated as hypertension is to prevent “falling down.” As the interviews evolved, it became evident that Haitians' perceptions of hypertension have a direct relationship with the fear of falling down and becoming unable to care for oneself and family. When asked, "Are you worried about your high blood pressure?” the conversations almost always led to a description of numbness and falling down. The tone of voice changed from one of explaining symptoms to one of expressing concern for what could happen if the pressure continues to get higher. Field observations describe encounters with non-participants who appear to have suffered a stroke previously and the impact on the caregiver. The following expert from the researcher's field journal describes a meeting from the clinic one day (March 2017):

> Today I was observing clinic in Coute Gorge, just outside of Domond. It was a hot sunny day with a clinic set up under a tree in a field. As I observed those in line waiting, I caught a glimpse of a young woman being carried to the front of the line in the arms of a man. My thought was that she had passed out from the heat while waiting in line. The woman was carried over to a "station" for evaluation. I walked closer to see if I could be of assistance. The man began to tell the nurse that she had been unable to walk or talk since giving birth three months prior. With tears in his eyes, he said she had been okay up until that day. Her arms were contracted, and she was completely non-verbal and non-weight bearing. Her blood pressure was documented as 212/102. It appeared as if she

> understood what others were saying but did not follow commands. The baby was being breastfed by the sister, which is common in Haiti when the birth mother is not able or away. The man continually begged for some medication to "make her better." The team comforted him and educated him on passive range of motion and frequent repositioning. They also discussed how to offer small sips of liquid and small bites of mashed food. After about 45 minutes, the man stands and carries her back home with tears still in his eyes. The team pauses and reflects on the inequities of health care for pregnant women and Haitians in general as compared to the United States. Within minutes, the chair is full again, and the team moves on.

Observations from the field supported the incidence of stroke in the Haitian population. This researcher's notes include pictures of wheelchairs made from lawn chairs and bicycle wheels and makeshift canes from pieces of wood. A few notes include older adults with contractures lying outside on grass mats and loved ones asking for help as the PI passes by. The PI stopped to talk with an older man on his porch, leading to an emotionally raw conversation. With tears in his eyes, he began to tell the story of his daughter as he looked over at her curled up on the concrete floor, as young children were playing next to her.

> “She needs to die. After she had her baby, she suddenly became numb and fell down. She could not speak or move. We called for help and they tell us that her ‘tansyion gro’ and caused her to be like this. There is nothing we can do. Her husband left her for work somewhere else and has not come home. Can you help her? There is no one to take care of her in this state.”

One participant in an interview emphatically proclaimed, "I would rather die than go numb and fall down."

Throughout interviews, stroke-like symptoms were discussed by each of the fifteen participants without a prompt from the RA, indicating the genuine fear associated with falling down. Stories and conversations regarding how to prevent

falling down and what causes one to fall down intrigued this researcher. The table below provides examples of quotes related to this phenomenon of falling down and depicts a representation of how Haitians fear this immensely. The powerfulness of the discussion and the richness of their descriptions of becoming numb or motionless or falling to the ground was an unexpected finding of the study and one that deserves closer examination in future studies.

Table 5.5

Stroke or Stroke-like Symptoms

Participant	**Evidential Quote**
1	I have a headache, and I have to *go fast* and take a rest and relax. If I don't just lie down immediately, I will fall because I can't resist. I have to hold onto a tree so I can stand and not fall down.
2	Yes, it is really, really, really scary because when you have it, you might be numb in one side and if you fall down and you can't get up, or you might be numb on one side forever. That is why I am so scared.
3	I don't want the high blood pressure to make me fall down so I just lay down before that happens.
4	You become numb.
5	I am so worried because if I don't try and contact a doctor, that can make me fall down and do nothing with my body.

6 When the high blood pressure is too high you have to be careful because if you fall down or you don't stay quiet then somebody just tries to grab you and after that you can feel this part is numb and it can kill you. This is what I know about the high blood pressure when it is too high.

7 If you fall down, you might be dead or your body not move.

8 When it reacts, that can make you fall down so I should be worried about it. This could make you feel numb or possible to fall down. So sometimes some people this used to kill them too. I remember there was a doctor close by the bridge, after the bridge in Domond, and he was sitting in a chair, and he had this kind of disease, and he falls down, and this killed him before going to the hospital. So when he got to the hospital, Lateme, he was already dead…passing away.

9 I am so worried about having high blood pressure because at any time it can make you fall down.

10 “Do you feel that when you are walking that you are weak? Do you feel that you cannot put one foot in front of the other?" The doctor thinks that if I continued like this, I could fall down and die.

11 High blood pressure can happen and make you feel bad until it kills you. And it can happen with the high blood pressure, and you get to the hospital, and you become numb, so this is a disease

	fatal.
12	You have to take care of it. Instead of being numb, I would rather die.
13	I went to fall, and the high blood pressure was reacting, and I was trying to grab a stand or tree. If I did not do that, I could fall and die at this time.
14	I am worried because that can make you numb or maybe kill you.
15	And when I stand, I am going to fall and then with the headache (mal tets) I feel like a little bit dizzy and almost fall. I feel like I become heavy, and I am going to fall down.

Meanings Inherent in the Themes

A review of the evolving themes and categories within the data provide a wealth of insight when examining how the Haitian population perceives the meaning of and beliefs about hypertension. Gaining an understanding of these perceptions is essential to healthcare providers to provide culturally competent care for this population. The realization that Haitians are incredibly fearful of ‘falling down' serves a catalyst for healthcare providers to gain a better understanding of how hypertension can and should be treated in this resource-limited population.

There are several meanings inherent in this data that are worthy of further discussion. The idea that hypertension is something that one “gets” as opposed to something that one “has”, impacts management practices. The data suggests

that Haitians do not think of the causes and symptoms of high blood pressure in terms of allopathic or modern medicine. Instead, Haitians equate hypertension as a feeling that may or may not be caused by a situational factor or lifestyle condition and, this feeling should be immediately treated.

The environmentally and culturally driven causes perceived to elevate blood pressure prevail in the discussions with participants. The data highlighting the Haitian adults' ability to recognize an elevation in blood pressure and the utilization of resources on hand to manage at that moment is suggestive of focus on "live in the moment" mentality. This mentality is often prevalent in resource-limited countries. Living day to day and managing situations as they occur is part of the Haitian culture. These findings are essential in that they highlight that allopathic medicine cannot be the only approach used when providing care in the Haitian population. The following chapter will give a more in-depth look at the meanings within the data, compare those findings with current literature, apply Kleinman’s EM of illness to hypertension in Haiti, and discuss future implications for the education of nurses in this area.

CHAPTER VI

Discussion of Findings

Through semi-structured interviews with participants and observations in the field, this focused ethnography research study sought to explore the perceptions of hypertension among Haitian adults and how those perceptions impact management of the disease. This research addressed the gap in the empirical research on culturally appropriate hypertension management practices in Haiti. The data analysis revealed that Haitians perceive hypertension as a feeling that one gets as a result of situational factors impacting their life at that moment. Haitians expressed that the need to treat this feeling immediately is crucial in preventing the act of falling down. Treatment of hypertension in the Haitian population is non-traditional, utilizing a variety of alternative methods with the occasional traditional medication as an option. Understanding the perception of hypertension in this population is crucial to the successful management of this disease. Health care providers must recognize that allopathic medicine cannot be the sole approach to hypertension management in the Haitian adult.

This chapter discusses the findings of the study, utilizing the theoretical framework of Arthur Kleinman, and identifies emerging questions and implications for the education of nurses and other healthcare providers. The limited health care infrastructure in Haiti contributes to the intermittent and supplemental medical care provided by visiting teams of nurses to the country. For visiting nurses, this research is valuable in providing a better understanding

of what hypertension is to the Haitian adult and how it is managed. Furthermore, this research highlights the importance of understanding that the meaning of disease differs among populations and that available resources for treatment contribute to this meaning.

Hypertension as a Feeling

The overarching theme identified in this research study is that Haitians perceive hypertension to be a feeling that one gets, which should be treated at that moment to prevent falling down. This feeling presents differently and can vary with occurrences and individuals. The feelings identified as being associated with hypertension can be a variety of symptoms to include headache, blurry vision, dizziness, burning, weakness, and shortness of breath. Haitians report a fear of falling down if one does not obtain relief from the feeling quickly. The phenomenon of falling down is described by participants as a result of "going numb, losing the ability to speak, and sometimes permanent inability to move one or all extremities". These feelings, known as symptoms in allopathic medicine, are consistent with presenting clinical manifestations of hypertension as well as consistent with the complication of stroke, often associated with uncontrolled hypertension. Haitians fear of falling down is presumed to be associated with the limited resources for survivors of stroke in Haiti, as well as the high incidence of mortality from stroke (Kenerson, 2014). During the interviews, several participants indicated that they would rather die than live after “falling down”. Kenerson (2014) supports this assertion by stating, "for individuals

disabled by stroke, further challenged by limited to no support resources*; it is 'hellacious'"* (p. `108).

Hypertension disease management is challenging in this population because Haitians do not treat it as a chronic disease. The focus of treatment strategies is more indicative of those utilized with acute illnesses with a goal of immediate and short-term symptom relief. Management of the presenting feeling is dependent upon the perceived cause and the resources available to assist. Overwhelmingly participants used alternative methods for control of their hypertension. A typical treatment option discussed by participants was a cold shower. The perception that high blood pressure is the result of "blood boiling" and becoming physically hot makes a cold shower a reasonable treatment option in the eyes of the Haitian. According to the literature, the opposite is true from a pathophysiological standpoint. Drastic changes from hot to cold such as that caused by a cold water shower, causes vasoconstriction resulting in increased blood pressure (Nall, 2019). Nonetheless, this option provides comfort and relief in the Haitian population in regards to what they perceive to be hypertension and is worthy of consideration.

Alternative treatment modalities among Haitians include limiting interaction with others and noise when they begin to experience a feeling such as anger or headaches. Participants added that stress as a result of arguing with someone is ultimately causing the feeling to manifest, and relief is obtained by removing oneself from the situation and "being quiet." Bokhour (2012) discussed daily-lived experiences (DLEs) contributing to high blood pressure. The DLEs pertinent

to the Haitian population included social relationships, lack of consistent routine, and prioritizing lifestyle choices. Recognizing the DLEs of the individual is vital to understanding the decisions made in symptom management. In other words, if the DLE of the individual is in an argumentative environment, then the option to remove oneself and find a quiet place is most likely therapeutic.

Along with DLEs, there are cultural aspects associated with the practice of treating the symptom of hypertension only when it presents in Haitians. It is not uncommon for people who live in resource-limited areas to be more focused "in the moment" as opposed to futuristic preventative action. This day to day survival mentality is a result of managing challenges as they present as seen with the participants who had prescribed medications for hypertension but only took the pill when not feeling well. While Haitians will agree that hypertension is something that you can "get" throughout your adult life, there is a lack of understanding that the disease is chronic and is most effectively managed daily, even when feeling well. The one identified strategy for reducing hypertension long term was related to daily dietary habits; however, there are cultural factors limiting adherence to the diet. Limitations pertaining to dietary modifications include types of food available, seasonings utilized in the cooking of the meals, and the lack of cooking methods associated with a stove/oven.

The current literature on hypertension in Haiti focuses on the prevalence of hypertension among gender and age groups, challenges with medication compliance, and the lack of focus on non-communicable disease management in

this country (Ibrahim & Damasceno, 2012; Kenerson, 2014; Mazzeo, 2013; Niska & Sloand, 2010).

The main gaps of knowledge in the literature found by this study include:

1. Exploration of available treatment options in rural Haiti for hypertension.
2. Suggested educational strategies that are realistic and culturally relevant.

This study addresses the gaps in the literature by highlighting the perceived causes of hypertension in Haiti and current management strategies utilized by Haitians, which are primarily impacted by culture and available resources in rural areas.

Participants in this study may not fully understand the medical diagnosis of hypertension. Still, they do understand and fear the consequences of untreated hypertension, as evidenced by the fear of falling down. Their knowledge of presenting symptoms of hypertension opens the door to expand on education and individualized treatment plans in this particular population. There is a need identified to meet the patient where they are in terms of knowledge, beliefs, and resources. Nurse researchers should investigate the opportunities to address the gaps in treatment associated with resource-limited populations.

Furthermore, nurses providing care in other countries with limited healthcare infrastructure and differing cultural practices must educate themselves before delivering care and education. Haiti is a short plane ride from the United States and is in dire need of health care, making this a frequent destination of

traveling medical teams. Culturally appropriate interventions and awareness of resources deserve further attention in areas such as rural Haiti to impact the WHO statistics on stroke and cardiovascular disease in this population.

Theoretical Framework

The Explanatory Models of Illness (EM) theoretical framework, developed by medical anthropologists, examines the individual's illness experience as "notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman, 1980, pg 105). Kleinman's EM, which helps to identify how patients perceive an illness, attempt to manage a disease, and prioritize interventions based on the value/effect, guided this research on the perception of hypertension among Haitian adults (Bokhour et al., 2012; Kleinman et al., 1978). Thus, this research study posits that the meaning of hypertension as an illness among Haitians can be best understood by learning what the clinical manifestations and causes of hypertension are and their management strategies. The findings of this research study also confirmed Kleinman's theory that EMs are comprised of both biomedical and psychosocial components; however, the psychosocial component prevails in the patient perception and management strategies utilized. Furthermore, although EMs are highly individualized, the theoretical framework led to insights regarding recommended interventions and education for patients with hypertension in Haiti and similar developing countries.

The overarching theme of this study, hypertension as a feeling one gets, was an unexpected finding that led this researcher to realize the complexity of

hypertension among Haitians. This complexity is contributing to the difficulty of managing hypertension in this population. The "feeling" helps to shape the perception of hypertension; however, it was more fully understood when examined with the self-management practices and believed causes of the illness. A comparison of the data in this study is congruent with other studies in the literature in that specific components of the EM were evident in the interviews: beliefs regarding the causes, presenting symptoms, and treatment options/resources. Also, the results of this finding indicated that the biomedical/pathophysiological explanation for hypertension is not prevailing among Haitians, as evidenced by their self-management practices, which are focused on psychosocial causes and treatment options (see Figure 6.1).

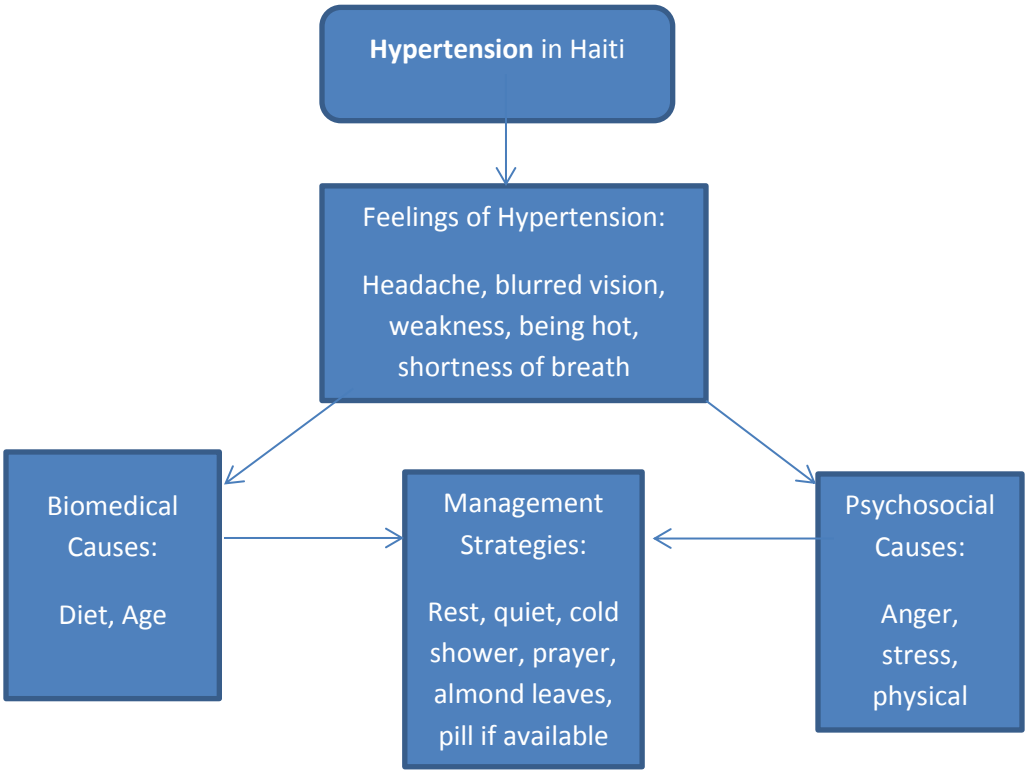

Figure 6.1. Proposed EM of hypertension for Haiti.

Haitians treat hypertension according to the feeling that emerges in an attempt to relieve it at that moment in time, thereby suggesting that hypertension is an acute and intermittent illness. These findings are similar to the results of Bokhour et al. (2012), who studied hypertension among veterans in the United States and found patient's reports of their EMs and beliefs about hypertension are more relevant to their self-management behaviors. Bokhours et al. (2012) also found that their population did not differentiate between acute and chronic illnesses. This ethnographic study highlighted the need to more fully understand the EM of hypertension in the Haitian community to impact future health outcomes by recognizing culturally appropriate interventions based on both beliefs and available resources.

Explanatory Model of Hypertension in Haiti

A generalized EM of hypertension in Haiti began to emerge in this study. Understanding this generalized EM provides the foundation for practitioners to then seek to understand the individualized EM of the Haitian adult. Haitians perceive hypertension as a feeling that one gets, which has the possibility of progressing to a state of falling down. These feelings present differently at times and among individuals. Haitians describe these feelings occurring as a result of a trigger or a cause. Commonly referenced causes in the interviews include stress, anger, being upset, working too hard, and diet. The findings of this study indicate that the perception among Haitians is that hypertension, while a lifelong disease, is treated as an acute illness. Management strategies are focused on relieving symptoms (feelings) when they present as opposed to preventing symptoms

from occurring. This idea of hypertension as an acute illness rather than a chronic disease is essential for healthcare providers to be aware of as they educate and treat in rural Haiti and similar areas. While participants did acknowledge that diet and age impact the likelihood of hypertension occurring, conversations tended to attribute the occurrence of hypertension as a result of something that is taking place at that moment in time. For example, many reported that becoming upset or being overworked caused the pressure in the blood to rise or "become hot" thereby resulting in the manifestation of the feeling. A less talked about cause of hypertension was related to doing evil resulting in spiritual consequences or a “curse”. The literature supports the cultural assumption that Haitians believe spirits and voodoo curses can result in health consequences (Etienne & Pavlovich-Danis, 2013; Vonarx, 2011).

Another unexpected finding of this study was the level of fear that surfaced when speaking with participants about hypertension. The participants reported a fear of becoming numb with the inability to speak and at times, move extremities. It was reported by the participants that this could be permanent and fatal. Their descriptions of the consequence of not alleviating the presenting feeling are similar to that of stoke, a known complication of hypertension in developed countries. This fear indicates that there is a level of understanding that hypertension does have implications if left unmanaged over time. This knowledge can be expanded upon when educating the population regarding the impacts of hypertension and the recommended treatment options.

As predicted by the theoretical model, the self-management practices help to explain the EM of hypertension in Haitian adults more fully. The self-management strategies utilized are dependent upon the perceived cause, presenting feeling, and available resources. The strategies emphasize that interventions are both economically and culturally driven. In terms of medication use, all participants felt that was the best method for relief; however, they only took the medication when the feeling presented and if they had a supply available. The notion of only taking medication when the feeling arises is indicative of a culture that rations available resources due to limitations of supply and money.

The most commonly used self-management practices in Haiti (quiet, calm, prayer, and cold showers) are supportive of a psychosocial EM due to limited resources and impacted by their DLEs. Mentioned previously, treatment of illness in Haiti typically includes consulting family members, spiritual healers, and alternative medicines such as almond leaves (Baptiste et al., 2018; Etienne & Pavlovich-Danis, 2013; Nicolas et al., 2006; Polsinelli et al., 2017; Vonarx, 2011). Haitians are known to turn to organized health care providers as a last resort often due to accessibility and limited finances. Participants mention the biomedical causes of age and diet; however, many feel helpless to make a difference as a result of the lack of foods and medications. As noted in the study by Taylor et al. (2012), although participants report knowledge of the disease and serious consequences, their response to recommendations for treatment are not always guided by this knowledge.

Implications for Healthcare Providers

This research examining the perception of hypertension among Haitian adults provides new information regarding educational approaches to managing chronic disease in resource-limited populations. Strategies based on allopathic medicine are the most effective according to evidence-based practice, which promotes medication compliance, dietary modifications, and increased exercise; however, this approach does not address the challenges present in developing countries (Kenerson, 2014). Health care providers must have a working knowledge of the EM associated with disease in the population being served. The ability to tailor education and suggest treatment options should consider the patient's EM and the resources available.

The findings of this study have implications for the treatment and education of Haitians living in rural Haiti. The main takeaway is to recognize that Haitians have an understanding of the symptoms of increased blood pressure and, more importantly, an understanding of the consequences of untreated high blood pressure. The opportunities for impacting the WHO statistics related to cardiovascular disease and the stroke rate in Haiti lies within the Haitian EM of hypertension. There is a need to find novel approaches to hypertension that encompass the social and behavioral aspects of the self-management practices of individuals to offer patient-centered care. Health care providers must capitalize on the available resources in the rural community as well as the believed causes of the feelings presenting as hypertension.

This research suggests that traditional medications, while perceived to be the best option by Haitians for relief from their symptoms, are not readily available. Kenerson (2012) recognized this in his discussion of evidence-based practice versus reality-based practice. He coined the phrase "best practice possible" to reflect the balance of the two. Best practice possible strategies are options that are effective in blood pressure reduction (best practice) and available and culturally appropriate (possible). Providers need to use an alternative "toolbox" for hypertension in resource-limited populations. The graphic below (Figure 6.2) depicts the contents of such a toolbox, as suggested by the findings in this study. Providers should take a holistic approach when addressing hypertension concerns and treatment options in Haiti. There must be an awareness of the tools both needed and available for the given population. Most importantly, the approach needs to be multifaceted (use all layers of the toolbox) while respecting cultural and spiritual beliefs.

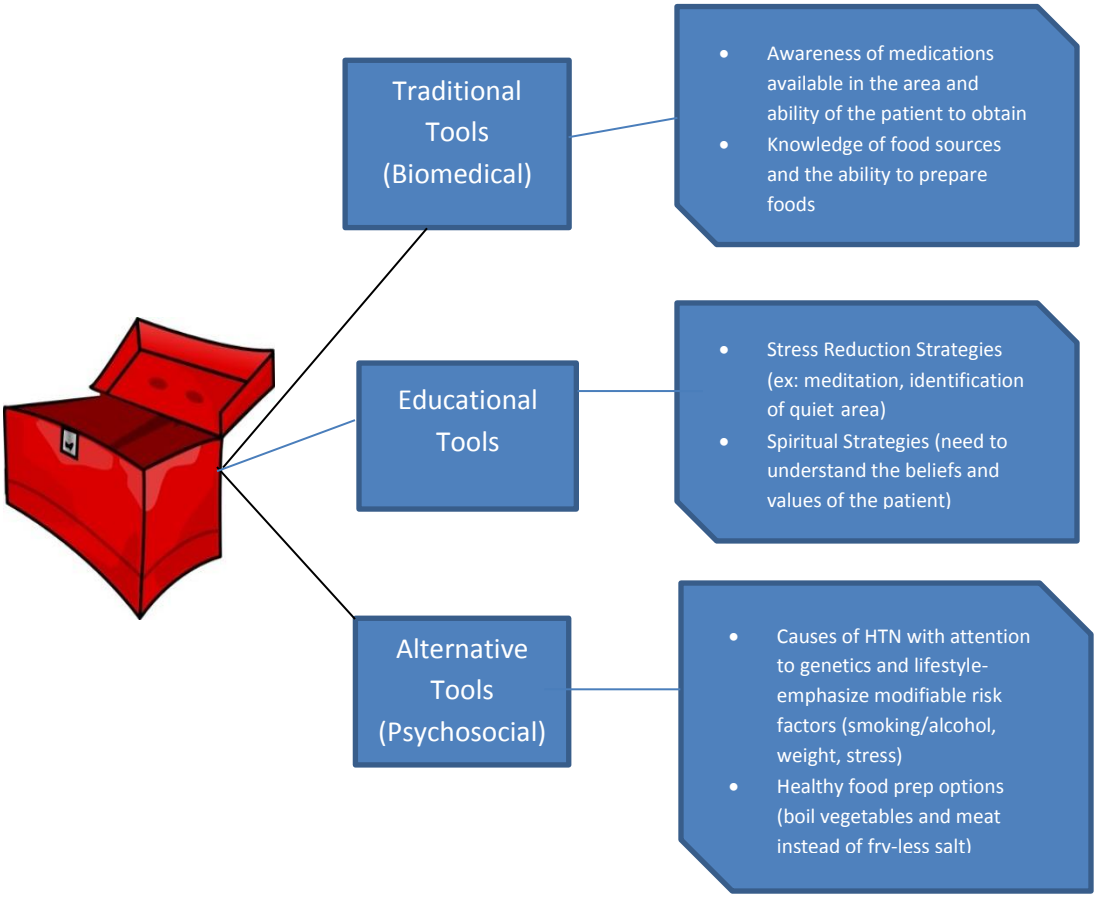

Figure 6.2. Toolbox for hypertension strategies in rural Haiti.

Summary

The overall theme identified in this study is that Haitians perceive hypertension as a feeling that is episodic and related to a specific incident or cause. As nurses and health care providers, it is crucial to have an understanding of the perception of diseases and their meaning to impact health outcomes of the population. Haitians in rural areas of the country do not have access to modern health care, ample medication supplies, or food options. Their homes are often one room with dirt floors and lacking an indoor kitchen and toilet. Their stress level can is attributed to daily hardships and physical labor.

Their focus is on the day to day survival. They are rich in their faith and support from others in the community. They rely heavily on those around them to provide and share the responsibilities of daily living.

Providers must gain an awareness of what tools are useful not only in specific populations but in individuals as well. For example, prescribing a hypertensive medication that cannot be filled in the local community or suggesting dietary limitations when food is in short supply does not offer a patient-centered approach to disease management. Understanding the meaning of hypertension in this population that has a high mortality rate from cardiovascular disease and stroke is vital to their quality of life. This study provides insights into the Haitian EM of hypertension. It offers information that can lead to a culturally appropriate and potentially impactful educational resource for the management of hypertension in Haitian adults.

CHAPTER VII

Conclusion

Summary

The WHO identifies hypertension as the most preventable form of death, estimating deaths due to cardiovascular disease will increase from 17 million in 2008 to 25 million in 2030 (WHO, 2014). Hypertension has been identified as the primary cause in 51% of stroke deaths and 45% of coronary heart disease deaths (WHO, 2014). Mortality data for Haiti indicates that the country has the highest reported stroke rate in North America and one of the highest reported stroke rates in the world, at 176 per 100,000 or 10.3% of deaths (World Life Expectancy, n.d.). Other complications of hypertension include atrial fibrillation, ischemic heart disease, peripheral vascular disease, renal disease, and retinopathy. Kenerson (2014) reports that 20% of deaths in Haiti are a result of hypertension and hypertension-related diseases. The most recent statistics posted by the WHO report Haiti with 545/100,000 deaths from communicable diseases and 697/100,000 deaths from non-communicable diseases in 2008 (World Health Organization, 2013). Despite these statistics, research examining the perceptions of Haitian adults concerning hypertension is noticeably lacking.

Guided by Kleinman's Explanatory Models of Illness theoretical framework (Kleinman et al., 1978), this research addressed the gap in the existing research examining the perception and meaning of hypertension in Haitian adults living in a rural village in the Central Plateau.

The research questions guiding this study were:

1. How do rural Haitians perceive hypertension as a health condition?
2. How do rural Haitians decide when medical treatment is needed?
3. What do rural Haitians believe about the treatment of hypertension?
4. How do rural Haitians perceive their ability to manage hypertension?

This study utilized a focused ethnographic methodology to describe the beliefs about and the meaning of hypertension in the Haitian population. Ethnography allowed the principal investigator (PI) to become immersed in the culture, thereby gaining familiarity with the language, socio-cultural norms, traditions, religion, family structures, and expressions of emotion. The PI spent a total of five weeks in the field listening, observing, and asking questions in an effort to understand the phenomenon being studied more thoroughly. One advantage of ethnography is the flexibility that is offered in this type of research. This flexibility allows the lived experiences of the participants to evolve in their natural setting. Focused ethnography provides the following additional advantages: 1) it is problem-focused and content specific; 2) ethnography focuses on a discrete community; 3) it involves a limited number of participants; 4) it included episodic participant observation; and 5) it can be used in the development of healthcare services (Cruz & Higginbottom, 2013; LeCompte & Schensul, 1999). LeCompte and Schensul add that focused ethnography is particularly appropriate and possible when the ethnographer is already somewhat familiar with the setting, culture, and population, as in this researcher's case. This methodology was appropriate for this study because the focus was on

one particular health condition in a discrete community that is familiar to the PI. Because little is found in the existing literature about hypertension treatment and control in the Haitian population, this method allowed for the obtainment of data that provided insight into the meaning of hypertension in this particular culture. With this insight, culturally appropriate strategies for disease management can be further developed and refined.

This research inquiry took place in the country of Haiti. Specifically, the study focused on the residents living in the village of Domond, Haiti. Recruitment of participants was completed during a routine clinic conducted by nurse practitioners and nurses at Voice of Victory church in Domond, Haiti, on a specified date that announced in Sunday services. The clinic was held at the Voice of Victory Church located in the center of the village. It was open to all regardless of religious affiliation, age, or reason for seeking care. The final sample size was 18 participants. Fifteen of the eighteen participants completed semi-structured interviews with the primary RA. In addition to semi-structured interviews, the PI and participants spent time in the community together at church, at the market, in homes, etc. over the eight months. Eleven of the participants were female (73%); males were more difficult to recruit due to being in the fields during daylight hours. Thirteen of the fifteen participants were between the ages of 41and 70 years old, with nine of those between 41 and 60 years of age. Fourteen (93%) reported having been previously diagnosed with hypertension before the recruitment day at the clinic, with 53% stating that they were currently taking medication for their hypertension. Of the eight participants

reporting current medication treatment, seven said their medication was aspirin (ASA). One participant showed empty bags labeled Hydrochlorothiazide (HCTZ) and Lisinopril and stated they had been out for about one week. At the time of enrollment, the mean systolic blood pressure was 167, and the mean diastolic was 102.

Data was collected through participant observations, individual semi-structured interviews, and casual conversations at different times of the day and on various days of the week over five weeks, divided into multiple trips. Each week's period consisted of 5-6 working days. These five weeks, coupled with the PI's previous experience and relationship building in the specified community, allowed adequate time for this focused ethnographic study. The total data collection time for this ethnographic study from start to finish was eight months. Semi-structured interviews designed to elicit specific information about hypertension from the perspective of selected Haitians living within a small, rural region constituted the primary source of data for this study. The PI had opportunities to inquire about hypertension as a health condition and learn about the decisions to seek treatment and follow treatment regimens. Interactions with participants in their various community settings (homes, churches, market, etc.) permitted rich observational experiences contributing data to explain how religious practices, social interactions, lifestyle habits potentially impact the management practices of hypertension in Haitian adults. This is the first study known to date that explored the perception of hypertension in rural Haiti to more fully understand the individual EM of hypertension to develop future strategies

with the potential to impact health outcomes of this deadly non-communicable disease positively.

Conclusions

The overarching theme identified in this research study is that Haitians perceive hypertension to be a feeling that one gets, which should be treated at that moment to prevent falling down. This feeling presents differently and can vary with occurrences and individuals. The feelings identified as being associated with hypertension can actually be a variety of symptoms to include headache, blurry vision, dizziness, burning, weakness, and shortness of breath. The phenomenon of falling down was described as a result of “going numb, losing the ability to speak, and sometimes permanent inability to move one or all extremities”. These feelings, referred to as symptoms in allopathic medicine, are consistent with presenting clinical manifestations of hypertension as well as consistent with the complication of stroke often associated with uncontrolled hypertension. Fear of falling was an unexpected finding of this study. Haitians fear of falling can be attributed to the limited resources for survivors of stroke in Haiti, as well as the high incidence of mortality from stroke (Kenerson, 2014). Participants indicated that they would rather die than live after “falling down”. This fear demonstrates that there is a level of understanding that hypertension does have implications if left unmanaged over time. This knowledge can be expanded upon when educating the population regarding the impacts of hypertension and the recommended treatment options.

Hypertension disease management is challenging in this population because Haitians do not treat it as a chronic disease. A generalized EM of hypertension in Haiti emerged in this study. As stated above, Haitians perceive hypertension as a feeling that one gets, which has the possibility of progressing to a state of falling down. These feelings present differently at times and are individualized. Haitians describe these feelings occurring as a result of a trigger or a cause. Commonly referenced causes in the interviews include stress, anger, being upset, working too hard, and diet. The findings of this study indicate that the perception among Haitians is that hypertension, while a lifelong disease, is treated as an acute illness. Management strategies are focused on relieving symptoms (feelings) when they present as opposed to preventing symptoms from occurring. This idea of hypertension as an acute illness rather than a chronic disease is important for healthcare providers to be aware of as they educate and treat in rural Haiti and similar areas. Although diet and age were recognized as having an impact on the likelihood of hypertension occurring, participants were more likely to attribute the occurrence of hypertension as a result of an incident taking place at that moment in time.

Congruent with the theoretical model, the self-management practices helped to explain the EM of hypertension in Haitian adults more fully. The self-management strategies utilized were directly related to the perceived cause, presenting feeling, and available resources. Their individualized strategies to manage the feeling of hypertension emphasize the economic and cultural aspects of the decision-making process. Medication use is an excellent example

of both of these aspects. All participants felt that medication was the best method for relief. However, they only took the pill when the feeling presented and if they had a supply available. The practice of only taking medication when the feeling presents, is indicative of a culture that rations available resources due to limitations of both supply and money. The “live in the moment” mentality contributed to the finding that Haitians perceive hypertension as an acute illness and therefore treat episodically when the need arises.

The most commonly used self-management practices in Haiti (quiet environment, calmness, prayer, and cold showers) are supportive of a psychosocial EM impacted by limited resources and influenced by their DLEs. Haitians are known to turn to organized health care providers as a last resort often due to accessibility and limited finances. Participants mention the biomedical causes of age and diet; however, many feel helpless to make a difference as a result of the lack of foods and medications.

The main gaps of knowledge in the literature found by this study include:

1. Exploration of available treatment options in rural Haiti for hypertension.
2. Suggested educational strategies that are realistic and culturally relevant.

This study addresses the gaps identified above by gaining an understanding of how Haitians perceive hypertension. Participants in this study did not fully understand the pathophysiological causes of hypertension. Still, they

did understand and fear the consequences of untreated hypertension, as evidenced by the great fear of falling down.

Strengths and Limitations

The findings of this qualitative study were based on sound focused ethnography methodology when conducting and analyzing the data from semi-structured interviews and field observations. The strengths of this research include the PI's relationship and familiarity with the area, people, and topics being studied. Having traveled to Haiti numerous times before the study, the PI had previously gained the trust and respect of the community. One limitation of the study is that the semi-structured interviews were conducted in one rural area of Haiti located in the Central Plateau and may not be reflective of all rural areas in Haiti or similar regions in other developing countries. Another limitation is the small sample size; however, this small size allowed for ample time with participants in both interviews and observations, adding to the richness of the data obtained.

Furthermore, due to the timing of the clinic when recruitment was completed, the majority of participants were female. The primary RA had previous experience with ethnographic research studies adding strength to the process utilized. Despite this experience, there is potential for the data to have been interpreted rather than translated in some instances.

Implications for Knowledge Generation and Practice

Eighty percent of all NCD deaths worldwide occur in low- and middle-income countries among people younger than 70 years of age, compared with an estimated 26% in high-income countries (WHO, 2014). The WHO 2014 statistics report 342 per 100,000 residents of Haiti die between the ages of 30 and 70 as a result of cardiovascular disease. This is regrettable because hypertension is a modifiable health condition; with proper control, hypertensive individuals can have a vastly higher quality of life. The research study helps to explain the EM of hypertension in Haitian adults, thereby revealing recommendations for nurses and other health care providers as well as implications for the education of nurses worldwide.

Recommendations for Nurses and Healthcare Providers

It is necessary to understand the perceptions of hypertension among Haitian adults as a first step to promoting adherence to treatment protocols and decreasing the risk of hypertension-related cardiovascular disease in this population. There is a need identified to meet all patients where they are in terms of knowledge, beliefs, and resources. Practitioners providing care in other countries with limited healthcare infrastructure and differing cultural practices must educate themselves before rendering care and education.

This research will help those providing care to hypertensive adults in rural Haiti understand that perceptions and treatment options are highly individualized. This study revealed that Haitian adults in the rural countryside of Domond, Haiti, commonly fear the consequence of falling down, widely known as a stroke in the

United States. It is this fear that prompts them to take immediate action on feelings associated with increased blood pressure. To further complicate things, the feelings vary from person to person, and treatment options are limited to the resources on hand.

The results of this study provide the following insights for delivering care that follow "Best Possible Practice" models for low resource areas:

- Perceptions of the disease/illness are individualized and give meaning.
- Physical and emotional feelings define the disease/illness for the individual.
- The presenting feeling (symptom) dictates the treatment modality used to relieve symptoms.
- Available resources and cultural beliefs dictate the method of treatment. Understanding what the best method of treatment does not mean that the method is a viable option.
- The need to act upon the feeling is driven by fear of further consequences up to and including death.

More specifically related to Haiti and hypertension treatment options, based on the results of this study, the following recommendations emerged:

- Gather information to determine the patient's perceived meaning of hypertension by merely asking, "how do you feel today?”. All interviews in this study started with that simple question and led to

a variety of stories and clinical manifestations, leading to the patient's perception of hypertension.

- Build trust with patients by engaging the patient in dialog that includes education and the encouragement of desired behaviors.
- Use clear, direct language to convey the message that hypertension is not an episodic condition.
- Support self-efficacy. Increase the patients' feeling that they have the power and resources to impact their health (Bandura, 2004).
- Gather information regarding current medication use to determine if the patient has or has previously used antihypertensive or ASA. If a medication is urgently needed, only recommend one that can be obtained locally.
- Educate patients about the benefits of daily medications such as stroke prevention, myocardial infarction, congestive heart failure, and kidney disease.
- Provide culturally relevant dietary recommendations to include limiting salt and fried foods when possible with an explanation of what to use in its place. For example, teach the patient how to boil their chicken as opposed to frying their chicken. It is not realistic to think that no seasoning will be used. Any reduction in use will be a worthwhile gain.
- Instruct patients to increase daily intake of potassium (fresh fruits and vegetables). Potassium is inversely related to blood pressure

and is associated with lower incidence of stroke (Staruschenko, 2018).

- Limit alcohol consumption-2 drinks/day for men and 1 drink/day for women (James, Oparil, & Carter, 2014).
- Incorporate and acknowledge aspects of spirituality in the disease process as both the cause of and treatment for hypertension. Encourage the patient to practice spiritual healing in accordance with their beliefs.
- Provide strategies for stress reduction and relaxation.
- Recommend moderate aerobic exercise such as brisk walking 5x/week for 30 minutes (James et al., 2014).
- Recommend smoking cessation (James et al., 2014).

Recommendations for the Education of Nurses

Global Health transcends borders and demands that nursing curriculums prepare future nurses to meet the healthcare needs of the vulnerable and resource-limited patients that they will inevitably cross paths with one day (American Academy for Colleges of Nursing, n.d.). This study emphasizes the importance of individualized, patient-centered care that is culturally appropriate. Nursing curriculums have mastered caring for the patient with common diseases and illness based on the recommendations of modern, evidence-based diagnostic testing and pharmacological therapy. Where programs are falling short is in teaching students the art of using their five senses to assess and diagnosis without the use of technology.

Furthermore, textbooks and evidence-based research are excellent at providing recommendations that are non-existent or unattainable for those in resource-limited countries such as Haiti. Nursing programs should provide opportunities for experiential learning outside of the walls of the traditional hospital where students can have the experience of asking questions and talking with others who may think differently than them based on differences in DLEs. Practicing the art of interviewing to explore EMs vs. completing a health history should be a skill focus for future nurses and other healthcare providers. It is in the understanding of the individual's perception of disease and disease management that providers have the highest chance at impacting health outcomes.

Final Thoughts and Recommendations

Although this study focused on a small sample of Haitians living with hypertension in rural Haiti, there is evidence to suggest that despite their poor conditions, the insights gained in this study may not be unique to just this population. The complexity of hypertension management in this population is the culmination of individual EMs, cultural beliefs, and available resources. Prior studies on hypertension in Haiti, all be it limited, primarily focused on prevalence statistics and mortality rates. Kenerson (2014) explored the pathophysiological causes of hypertension among Haitian adults but failed to recognize the importance of psychosocial contributors to the disease. This study utilized a theoretical framework for exploring hypertension among Haitian adults that led to valuable details explaining the perception and meaning of hypertension in this population. It is with these details that nursing can make future recommendations

that can impact the care and management of hypertension, and potentially other chronic diseases, by incorporating culturally appropriate and individualized treatment plans for patients in resource-limited populations.

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Appendix A: Performing an Ethnographic Interview and Securing Data

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Outline of PowerPoint Education Provided to Research Assistants

Interview Setting

- The interview should take place in a setting that allows for minimal interruptions and privacy. The ideal setting would be the grounds of the Louise Mulligan Mission house in Domond as it is centrally located and offers privacy.
- An alternative site for interview is the Voice of Victory church which is also centrally located.

Review of Steps in the Interview Process

- Introduce self to the participant
- Explain purpose of study (see interview guide)
- Explain length of interview
- Discuss need for possible additional interviews for clarification
- Discuss purpose of audio taping with participant (see interview guide)
- Obtain Oral Consent for interview and audio recording.

Equipment Needed for Interview

- Interview Guide
- Pen and Paper
- Interview Log/Reflexive Journal (note: participant name, participant #, date of interview, start and stop time of interview)
- Water for self and participant
- Automatic Blood Pressure Cuff (participants will expect their blood pressure taken as it is a study about HTN although the purpose of this visit is not about obtaining blood pressure)
- Blood Pressure Guide outlining ideal blood pressure parameters
- Tape Recorder and Batteries
- Laptop for after interview to download files from recorder

Special Considerations

- Encourage participant to come alone to allow for comfort/privacy in answering questions.
- If participant comes with children, offer children coloring book and crayons to keep them busy.
- Do not allow others to “join” the interview or sit nearby and listen. Ask those that show up at interview to leave the area.

- Pay attention to audio tape to monitor continued recording.

Once Consent is Obtained

- Collect demographic data, log patient name into log book and assign a **participant number**. This number should be used to identify participant on audio file, demographic information, and any field notes that are done from this point forward.
- Begin audio tape. Press Record to begin.
  - Verify that each new interview is a new file on the recorder
  - Begin by stating **participant number**
- Start interview with obtaining participant blood pressure and let them know what the blood pressure is (high, low, normal).
  - State BP on audio file to begin the interview. Review with participant the significance of their BP.
- Using Interview guide begin questions starting with the Grand Tour questions.
- Allow participant to tell their story.
- Use follow up questions for re-direction if needed or to solicit elaboration of details.
- Seek clarification as needed without “suggesting” words to participant.

Length of Interview

- The interview should be approximately 1 hour and cover questions outlined in interview guide.
- If more time is needed, participant should be asked if it is okay to continue or if they would like to come back at another time

Closing Question

- Wrap up the interview session with: “Is there anything else that you would like to share with me today about your “tansyion”?

Ending the Interview

- Once questions have been completed or time is up, thank the participant for coming and sharing their story with you. **STOP RECORDING**
- Let participant know that the study will take some time to complete and they may be asked to come talk with us again.
- Encourage the participant to continue to monitor their blood pressure when there are clinics held at the church.
- Assist/Walk client to exit and thank them once again.

After Participant Leaves:

- Verify log is complete (participant name, assigned number, date, start/stop time)

- Check battery level indicator on recorder. If indicator is <50% battery life, change batteries.
- Place old batteries in bag provided by Primary Researcher.

Steps to Sending Audio Files

Audio files should be downloaded at the end of each "working day"

- Connect Sony recorder to laptop using USB cord located in equipment box
- Select file from menu folder located on Sony Recorder
- Open 'SO' on laptop (this is the software for the recorder)
- Select Import New Files
- Open Music Folder and Sound Organizer Folder
- Open your email
- Create email to amy_feurer@bshsi.org
- Add file from sound organizer folder to email as attachment
  - You may only send one file per email
  - Due to email size, file upload may take a few minutes
- Encrypt email
  - See next slide for details on email

- Send email to amy_feurer@bshsi.org
- Repeat until all new files have been sent
- DO NOT ERASE FILES FROM SOUND ORGANIZER FOLDER on laptop UNTIL INSTRUCTED TO DO SO BY Amy
- File may be erased from recorder once email is sent

How to Send Encrypted Email

- **Open new email message to amy_feurer@bshsi.org**
- **Contents of email should include:**
  - **Participant ID # only, name is not needed**
  - **Date of interview**
  - **File attachment**
- **Encrypt a single message**
- In the message, on the **Message** tab, in the **Options** group on the ribbon, click the **Encrypt Message Contents and Attachments** button .
- **Note** If you don't see this button, click the **Options Dialog Box Launcher** in the lower right corner of the group to open the Message Options dialog box. Click the **Security Settings** button and in the Security Properties dialog box, select **Encrypt message contents and attachments**. Click OK and then close the Message Options dialog box.

- Compose your message and send it.
- Once email is sent, erase file from the audio recorder

Final Steps

- Place bag, log, and other interview supplies in designated locked box located at Louise Mulligan Guest House.
- Close all files on laptop and log off.
- Audio files imported to laptop should not be erased until notified to do so by Amy. Audio files on laptop should only have participant # identified in recording. NO participant name should be attached to audio file on laptop at anytime.

Appendix B: Translator Confidentiality Form

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Translator/Research Assistant Confidentiality Agreement Form

Title of Study: Perceptions of Hypertension Among Haitian Adults: A Focused Ethnography

I, _____, understand that I am being asked to work as a translator for Amy Feurer, a doctoral student at Rutgers, The State University of New Jersey, School of Nursing. I am aware that all information obtained as a result of the work with this study shall remain confidential. I understand that I am not to talk about the participants' involvement with this study with anyone other than Amy Feurer.

By signing this form, I agree to keep all information received as a part of this research confidential.

Translator Name:_____

Subject Signature:_____ Date:_____

Appendix C: English Consent Script

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SCRIPT FOR CONSENT TO TAKE PART IN A RESEARCH STUDY

Title of Study: Perceptions of Hypertension Among Haitian Adults: A Focused Ethnography

I am Amy Feurer, a doctoral student at the Rutgers, The State University of New Jersey, School of Nursing. I am a PhD student conducting a research study. Sometimes other people will work with me, such as translators. I would like to tell you about a study that involves Haitian adults like yourself. I would like to see if you would like to participate in this study.

I am doing this study to learn more about the meaning and beliefs of high blood pressure for Haitian adults. I want to learn what you know about high blood pressure and what the term high blood pressure means to you.

You have been asked to take part in this study because you have high blood pressure.

Haitian adults living in Domond, both male and female, over the age of 18 can participate in this study. Participants must have a blood pressure of 140/90 or greater in order to be selected for participation.

You cannot participate in this study if you are pregnant, less than 18 years of age, or not able to complete the interview process. The participant will spend approximately 1 ½ hours in an interview.

This study will take place over a period of three- six months.

If you choose to be in this study, I may ask to come to your home to see your house and meet your family. I will also be staying in your community and observing what kinds of activities you do during the day. I will ask you questions about your blood pressure. I will take some notes and tape our conversations. You will be able to know what all of my notes say. I will have a translator working with me every time I see you.

I will not be offering medication to you for your high blood pressure. I cannot "cure" your high blood pressure. I will offer ways for you to monitor your blood pressure and information that may be helpful for you to lower your blood pressure without medication. If your blood pressure is making you feel sick, I will work with the community leader and clinics to seek treatment for you. I cannot provide you with the medication to treat your high blood pressure.

Sometimes things happen to people in research studies that may hurt them or make them feel bad. These are called risks. The risks of this study are:

1. *You become more worried about your health as result of our conversations*
2. *You feel like you cannot do anything to change your blood pressure*

3. *Others in the community may see you talking with me and learn that you have high blood pressure*

You don't have to be in this study if you don't want to. No one will get angry or upset if you don't want to be in the study. Just tell us. And remember, you can change your mind later if you decide you don't want to be in the study anymore.

You will receive a small gift for participating in the study.

You can ask questions at any time. You can ask now. You can ask later. You can talk to me or you can talk to someone else at any time during the study. I will be staying in the Mission guesthouse across from the church in Domond. If you need me, Pastor Franck Marcellin will be able to get me both while I am in Haiti or back in the United States.

I understand that I have the right to ask questions about any part of the study at any time. I understand that I should not sign this form unless I have had a chance to ask questions and have been given answers to all of my questions.

Here is the contact information should you have any questions at any time:

To contact Amy Feurer using Pastor Franck:

- *Go to Voice of Victory Church to speak with him and he will contact Amy Feurer*
- *Call Pastor Franck on his cell phone at:*

To Contact Amy Feurer directly:

- *Call me, Amy Feurer, on cell at:*
- *Email me: amy_feurer@bshsi.org*

If I have any questions about my rights as a research subject, I can call:

Chair, Institutional Review Board ***and/or*** *IRB Director*

Appendix D: Audio/Videotape Verbal Consent Script

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AUDIO/VIDEOTAPE VERBAL CONSENT SCRIPT

Title of Study: Perceptions of Hypertension Among Haitian Adults: A Focused Ethnography

You have already agreed to participate in a research study conducted by Amy Feurer. We are asking for your permission to allow us to audiotape our conversations as part of that research study.

The recording(s) will be used for

- ***Review by Amy Feurer as part of the analysis of the study***

The recording(s) will include the conversation between you and the primary research assistant, Louis Thony. Your identity will not be included in the recording. The recording(s) will be stored on a password protected computer by the research assistant and Amy Feurer. The recordings will be kept for a period of three years.

Your verbal consent grants the research assistant named above permission to record you as described above during participation in the above-referenced study. The recording(s) will not be used for any other reason than that/those stated above without your written permission.

Do you agree to audiotaping as part of this research study?

Appendix E: Demographic Data Survey

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Title of Study: Perceptions of Hypertension Among Haitian Adults: A Focused Ethnography

Demographic Data

Q1. Gender

- Male
- Female

Q2. Age

- How old are you? _____

Q3. Marital Status

- Single
- Married
- Divorced
- Widowed

Q4. Work

- Do you work for pay?
  - Yes

        - What type of work do you do?
    - No

Q5. Housing

- House
- Tent
- Other
    - _____

Q6. Living arrangements

- How many people live with you?
- What is their relationship to you?

Q7. Do you smoke tobacco?

- Yes
- No

Q8. Do you drink alcohol?

- Yes
    - If yes, how much per day do you drink?
- No

Q9. How many meals a day do you eat? _____

Q10. How is your food prepared? (Select all that apply)

- Charcoal Fire
- Oven
- Fried in grease
- Boiled
- Raw

Q11. Have you been told that you have high blood pressure before?

- Yes
- No

Q12. Have you been given medication for high blood pressure before?

- Yes
- No

Q13. Are you currently taking medication for high blood pressure?

- Yes
- No

Q14. Vital Signs

- Height
- Weight
- Blood Pressure
- Pulse
- Temperature

- Pain Level (using FACES scale)

Appendix F: Interview Guide

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Title of Study: Perceptions of Hypertension Among Haitian Adults: A Focused Ethnography

Interview Guide

Introductions/Explanation

At the start of every interview participants will hear a brief explanation about the nature of the interview and the purpose of the research.

The following explanation will be offered to participants at the start of the interview:

> ***The reason you have asked to come share with me is so that I can ask questions related to high blood pressure and your health. This is a research study to learn about what blood pressure is, how you treat blood pressure if it is high, what it feels like to have high blood pressure, and what causes blood pressure to be high. This research will be used to learn about high blood pressure in Haiti. The information that is received will be used to help nurses and doctors improve blood pressure in Haiti.***

Recording Explanation

Participants will be informed about the method of gathering data in the interview for future reference.

> ***To keep up with information received, your name will be recorded in a log with an identification number. The identification number will be used on the audio tape but not your name. I would also like permission to record our conversation so that I do not have to write down so much while we are talking; will that be OK? See Appendix D and read script.***

Interview Explanation

Each interview will begin with obtaining the participant's blood pressure. This will provide a lead in to the discussion and focus the interview on hypertension. This explanation will tell the participant what to expect about the interview process.

> ***I would like to begin our conversation today by taking your blood pressure and talking about how you are feeling today.***

Questions for Interview

Using Spradley's method of ethnographic interviewing (Spradley, 1979), the following questions have been developed for use in this study.

Grand Tour Question

1. What does it mean to be healthy?
2. What kind of illnesses do you have?

3. What do you or people from your family call high blood pressure? (use the participant's terminology for high blood pressure in future questions)

Specific Grand Tour Question

1. When did you learn that you had high blood pressure?
    a. Who told you?
    b. What did they tell you was wrong?
    c. Did they give you any medication?
2. Why do you think you have high blood pressure?
3. What do you think causes high blood pressure?
4. Describe how your body feels with high blood pressure.
5. When you are feeling sick or you feel like your blood pressure is high, what kinds of things do you do on your own to make yourself feel better?
6. Are you worried about your blood pressure? Why or why not?
7. Do you think that high blood pressure needs to be treated with a medication?
    a. Why do you think this?
8. Is there anything else that you can do to take care of high blood pressure?
9. What makes it hard to get your blood pressure lower?

Guided Mini-Tour Questions

1. Can you tell me what you what do you do to treat your high blood pressure?

2. Can you give me an example of something you do that makes you feel better?
3. Is there anything that you do to that makes your blood pressure lower when you think it is high?
4. What role, if any, does your faith play in making decisions about your health?
5. What do your family members say when you tell them you have “high pressure” or that you do not feel well?
6. What types of things do you do that you feel make your blood pressure higher?

Closing Question

All interviews should end with the following question:

Is there anything else you would like to share with me today about high blood pressure?