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**The Lived Experience of Haitians with Mild Cognitive Impairment
in South Florida: A Phenomenological Inquiry**

Marie Bernadette Samson-Joseph

THE LIVED EXPERIENCE OF HAITIANS WITH MILD COGNITIVE
IMPAIRMENT IN SOUTH FLORIDA:
A PHENOMENOLOGICAL INQUIRY

DISSERTATION

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Marie Bernadette Samson-Joseph

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2016

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Abstract

Background: Mild cognitive impairment (MCI) is a syndrome that affects individuals' cognitive processes. While MCI does not affect the person's ability to function, it does affect the intellectual abilities of the individual. Regardless of the etiology, MCI negatively affects the well-being and safety of the individual. The target population for this inquiry was Haitians 55 years and older who live in South Florida. A gap in the literature exists regarding Haitian patients with MCI. The literature review revealed a lack of research on Haitians with MCI.

Purpose: The purpose of this qualitative phenomenological inquiry was to explore the lived experience of Haitians with MCI in South Florida. This phenomenological research aimed to understand and to describe the essence of the experience of Haitians living with MCI in South Florida.

Philosophical underpinning: A qualitative study using phenomenology guided by Max van Manen's approach was used.

Method: The qualitative research question guiding this inquiry was: What is the lived experience of Haitians with Mild Cognitive Impairment in South Florida? A purposive sampling of 21 participants was recruited from medical clinics, churches, and regularly frequented community centers visited by Haitians throughout South Florida. Data collection consisted of semi-structured interviews. Max van Manen's data analysis process was used to explore and gain understanding of the resultant data.

Result: The results revealed a myriad of feelings regarding MCI. Four main themes and two subthemes were identified during the data analysis process.

Conclusion: The inquiry concluded by identifying four themes and subthemes: *Blaming*, *Stigmatizing - Fearing*, *Doubting*, and *Spiritualizing - Praying*. These themes connected best with the Reconceptualized uncertainty of illness theory (RUIT). The RUIT assisted the researcher in clarifying and further understanding the lived experience of the Haitians with MCI in South Florida.

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Give thanks to the LORD for he is good, His mercy endures forever!

Psalms 107:1

I thank God for his continued blessings. May God continue to bless and guide us forever!

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“Strength does not come from physical capacity. It comes from an indomitable will”

Mahatma Gandhi

DEDICATION

To my two precious gifts, *Chevara* and *Chloe*. I never thought such love existed until I meet the two of you. My lamb and my lion. So different and so alike at the same time. You truly rock my world!!! I thank God for you. You both are wonderful, beautiful, and very smart. You are so amazingly funny and well rounded; I am impressed with your maturity levels. By the grace of God, set the skies as your limits. This book is for you both, whatever endeavor you undertake, complete it; do it with pride, be proud of who you are. Keep your chins up. Never give up. If at first you don't success, pick yourself up and try again. Never give up. Never lose faith. Trust God always. Please follow the advice of the song "*I Hope You Dance.*"

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CHAPTER ONE

Human beings experience different manifestations of aging. Although many older adults age successfully, others experience many problems. For the purpose of this inquiry, the problems with cognition were explored. Cognitive problems, which are one of the health concerns that the elderly experience, could be related to many factors such as infection, tumor, or symptoms from chronic illnesses. Older adults are susceptible to memory problems after the age of 60 (Lin, Vance, Gleason, & Heidrich, 2012). One type of memory problem is mild cognitive impairment (MCI), which is a serious concern since it has the potential to affect the individual's way of life or well-being. The purpose of this qualitative philosophical inquiry was to understand the lived experiences of Haitians with MCI in South Florida.

Problem and Domain of the Inquiry

Background of the Study

The phenomenon of interest, which was to understand the essence and the meaning of mild cognitive impairment from the lived experience of Haitians in South Florida, was explored. This section discusses the domain of the inquiry. Background information is provided on MCI, Haiti and its people, and Haitians in South Florida. In addition, this chapter discusses the statement of the problem, purpose of the study, research question, philosophical underpinning, significance and implications of the study, and finally, the scope and limitations are discussed.

Mild Cognitive Impairment

Definition. Mild cognitive impairment is a syndrome that affects individuals' cognitive processes. While MCI does not affect the person's ability to function, it does

affect the intellectual abilities of the individual (Petersen, 2011). Mild cognitive impairment is clinically defined as a “mild decline in either single or multiple cognitive domains—such as memory, executive functioning, attention, or visuospatial abilities—while global cognition and basic activities of daily living remain intact” (Lin et al., 2012, p. 22). There are two subtypes of MCI: amnesic and nonamnesic. The amnesic MCI is simply categorized as an increase in forgetfulness while functional abilities and other cognitive capacities remain intact for the most part. On the other hand, nonamnesic, a less common type of MCI, is defined as an insidious functional decline that is often associated with frontotemporal lobar degeneration or Lewy Body dementia (Petersen, 2011). Nonamnesic MCI is typically “not related to memory, affecting attention, use of language, or visuospatial skills” (Petersen, 2011, p. 2227).

It is normal for the memory to be impaired during normal healthy aging; therefore, the diagnosis of MCI might be perplexing for individuals and their families since the etiology of the illness might be unknown. Additionally, the person might have some comorbid condition that might cause confusion in diagnosing (Albert et al., 2011; Belleville, Gauthier, Lepage, & Kergoat, 2014; Gauthier et al., 2006). The person might still be able to perform the following basic and instrumental activities of daily living: drive, use the telephone, travel alone, go grocery shopping, manage medication, prepare food, locate lost items, and handle finances (Lin et al., 2012). Several changes might occur secondary to MCI—for example, loss of independence, food handling safety, loss of income from work, and more support needed from family members. The worst outcome of MCI is that it could progress to dementia, or it might be the precursor to another illness such as a tumor. Consequently, anxiety, severe cognitive impairment, and

mood disorders are frequently related to MCI (Lin et al., 2012; Patterson, 1989; Petersen, 2011). There are some reversible factors of MCI such as side effects from medications and trauma, vitamin B12 deficiency, infection, or acute cerebral vascular accident (CVA). Mild cognitive impairment might mimic other symptoms such as depression, or it might appear during chronic diseases similar to congestive heart failure (CHF); such complications make MCI difficult to be recognized and treated (Gauthier et al., 2006). The Centers for Disease Control and Prevention (CDC, 2011) estimated that over 16 million people have cognitive impairment in the United States. By 2050, that number is expected to dramatically increase as the baby boomer generation ages.

The most common form of cognitive impairment is Alzheimer's disease, which is a more moderate to severe type of cognitive impairment. It is expensive to care for persons with cognitive impairment; notably, the cost is often related to hospital care, which burdens the health care system (CDC, 2011). Family members and friends often provide unpaid care to the person affected. Alzheimer's disease causes these individuals to lose income from work and causes a great deal of stress to cope with the impairment. It is estimated that 17% of the population in Florida is perceived to suffer from some form of cognitive impairment (CDC, 2011).

The incidence of MCI appears to be higher in men than in women (Feldman & Jacova, 2005). According to Weybright, Dattilo, and Rush (2010), the overall prevalence rate of MCI in the community is 3% to 29% in adult 65 years and older, whereas the institutional prevalence rate of MCI is usually close to 61%. Since there are no standardized criteria to measure MCI, "MCI is especially troublesome as a diagnosis

because it is viewed as a period between normal functioning of the older person's brain and dementia, most notably, Alzheimer's disease" (Feldman & Jacova, 2005, p. 645).

People with MCI have a higher risk of developing dementia, particularly Alzheimer's disease (AD) (Lin et al., 2012; Petersen, 2011). Usually self-reported as a memory problem, the forgetfulness associated with MCI is often confirmed by a spouse or child as the collaborator or informant (Weybright et al., 2010). About 13.5% to 44% of individuals with MCI either revert back to normal cognitive function or remain stable (Belleville et al., 2014).

Symptoms. Each person experiences the normal aging process differently; some people develop mental and physical impairments and diseases while others do not (Beers & Berkow, 2000; Feldman & Jacova, 2005). The brain, like the rest of the body, changes over time, and some people may experience gradual forgetfulness as they age. Progressive and increasing changes in cognitive function is not normal (Lin et al., 2012). Forgetting more events, inability to concentrate, showing increased poor judgment or impulse behaviors are some signs of MCI. The individual may experience depression, irritability and aggression, anxiety, and apathy (Mayo Clinic, 2012).

Causes. The presentation of MCI depends on its etiology. A specific singular cause or outcome associated with MCI does not exist. The cause or origin of this syndrome is based on the pathology of the brain (Lin et al., 2012). Neurofibrillary tangles and temporal lobe atrophy have been found in patients with amnesic MCI. Patients who have experienced small strokes or reduced cerebral blood flow have been found to progress to vascular dementia (Lin et al., 2012; Mayo Clinic, 2012).

Risk factors. The risk factors associated with MCI are “advancing age, family history of Alzheimer’s or another dementia, and conditions that raise risk for cardiovascular disease” (Alzheimer’s Association, 2012a, p. 2). Cerebrovascular disease and neurodegenerative features have been found to be associated with MCI such that white-matter lesions and lacunar infarcts are great offenders of vascular cognitive impairment (Gauthier et al., 2006). Lifestyle factors and other medical conditions, such as diabetes, smoking, depression, high blood pressure, high cholesterol, lack of physical exercise, and lack of mental or social stimulation, have all been associated with increased risk of cognitive impairment (Lin et al., 2012; Mayo Clinic, 2012). Once biomarkers for beta-amyloid protein ($A\beta$) and neuronal injury are negative, in conjunction with other neuropsychological testing, dementia must be ruled out as a diagnosis; subsequently, the primary cause of the MCI syndrome must be determined (Albert et al., 2011).

Tests and diagnosis. No specific tests can confirm a diagnosis of MCI; however, to accurately identify MCI syndrome, the following process needs to be executed: (a) a thorough history and physical; (b) functional test; (c) laboratory testing, magnetic resonance imaging (MRI), or positron emission tomography (PET) imaging; and (d) cognitive testing such as the Free and Cued Selective Reminding Test, Rey Auditory Verbal Learning Test, California Verbal Learning Test, Logical Memory I and II of the Wechsler Memory Scale Revised, Visual Reproduction subset of the Wechsler Memory Scale, Trail Making Test, or the Boston Naming Test based on the cognitive domain being assessed (Albert et al., 2011).

The boundaries of aging and dementia are often tested by various measures including but not limited to neuropsychological tools and clinical judgments. Tests such

as the clinical dementia rating (CDR), and the Global Deterioration Scale for aging and dementia (GDS), and the Mini-Mental State Examination (MMSE), are often used to assist in measuring the severity of the impairment. No single test is conclusive or predictive of MCI (Belleville et al., 2014; Bush, Kozak, & Elmslie, 1997; Feldman & Jacova, 2005; Gauthier et al., 2006; Weybright et al.; 2010). According to Albert et al. (2011), “virtually all cognitive tests are sensitive to differences in age, education, and/or cultural variations among individuals” (p. 5), which means they are biased against certain cohorts of people. Laboratory tests and PET or MRIs are used to study the structure of the brain to rule out other pathologies (Alzheimer’s Association, 2012b; Feldman & Jacova, 2005). Both objective and subjective reports of cognitive deficits with the preservation of activities of daily living need to be present to establish a clinical diagnosis of MCI (Albert et al., 2011).

Treatment and drugs. It is important to remember that there are no medications to treat MCI; it is a clinical condition. Based on the presentation and the medical workup, the symptoms and underlying causes of MCI can be treated effectively. With treatment of the appropriate underlying factors, MCI should be ameliorated, resolved, or prevented. Several strategies have been found useful in controlling the factors that are associated with MCI, such as exercising, controlling cardiovascular risk factors, engaging in mentally and socially stimulating activities, and using effective coping strategies. The Mayo Clinic (2012) wrote that overall good health has been shown to play a role in good cognitive health. These factors have all been found to be beneficial for overall well-being of the person affected (Alzheimer’s Association, 2012b; Feldman & Jacova, 2005;

Weybright et al., 2010). If not resolved, reevaluation of MCI is recommended every 6 months and as needed (Alzheimer's Association, 2012b).

Cultural perspective. Based on what is known about cognitive impairment, it does not discriminate among people. While there is no statistical information to quantify the following statement, people suffer from MCI from all cultural and ethnic cohorts. The United States is a melting pot of many people from all walks of life; this diversity of the United States population is not reflected in its research efforts. There is a need to conduct empirical studies that emphasize ethnicity because an individual's health perception and belief might be different among the different cultural groups. While writing about issues related to dementia, Harwood, Barker, Ownby, and Duara (2000) explained that "it is clear that continued research in the area of ethnicity and dementia is warranted to better understand the clinical needs of Blacks and other minority populations in the United States that are afflicted with AD" (p. 424).

Madeleine Leininger wrote that "Nursing is a transcultural humanistic and scientific care discipline and profession with the central purpose to serve human beings worldwide" (as cited in Welch et al., 1998, p. 447). Leininger continued to reiterate that "every human culture has certain generic (lay, folk, or indigenous) care knowledge and practices that varies transculturally" (as cited in Welch et al., 1998, p. 447). The goal of transcultural nursing is to discover the emic views of the culture and in turn use professional epic knowledge to guide the delivery of care practices (Welch et al., 1998). As highlighted by Sun, Ong, and Burnett (2012), emotional well-being is affected by cultural beliefs; the diagnosis of dementia might cause undue stress secondary to the potential linkage to the stigma of mental illness. Sun et al. (2012) ascertained that

because the population is rapidly growing, more research is needed to ameliorate racial/ethnic disparities in terms of prevention and intervention regarding dementia. The researchers recommended rigorous research that incorporates Chinese cultural and family values so that the population can receive better services. The researchers emphasized that the prevalence of cognitive disease is increasing and so must the research on the population that is most affected by it.

Global health. One goal of global health initiative is to improve the health and well-being of people around the world. Globally, the World Health Organization (WHO) (2010) defines health as “a state of complete physical, mental, and social well-being not just the absence of disease” (p.9). On the other hand, mental illness is viewed as “an alteration in thinking, mood, or behavior associated with distress and/or impaired functioning” (CDC, 2013, p. 1). The global health initiative from Harvard Medical School stated:

Mental health problems impose a serious and widespread health burden, yet remain a neglected and under-resourced domain of global health. Lack of access to safe and effective services remains a significant barrier to mental health care globally; Stigma related to mental disorders prevents those afflicted with mental illness from seeking access to mental health care, and ultimately compromises their human rights. (Raviola, 2015, para. 1)

Well-being is defined as the perception of satisfaction in life and the meaning of that satisfaction; it is a determinant of the quality of life of the individual (CDC, 2013).

The CDC (2013) defines three distinctive indicators of mental health:

1. Emotional well-being – refers to happiness, cheerfulness, peacefulness, and perceived life satisfaction (p. 1).
2. Psychological well-being – refers to personal growth, self-acceptance, optimism, hopefulness, spirituality, purpose in life, positive relationships, self-direction, and control of one’s environment (p. 1).
3. Social well-being – refers to social acceptance, sense of community, personal self-worth and usefulness to society, beliefs in the potential of people and society as a whole (p. 1).

The more industrialized nations have health care initiatives and health care policies and systems to better support their citizens’ physical and mental health. In the United States, many private and public health care agencies exist, as do policies geared to assist the citizens with their physical and mental ailments. One such agency is the Alzheimer’s Association. While specific information about MCI is not available on different cultural groups or subsets, extensive information on Alzheimer’s disease, which could become one of the end products of MCI, is available from the Alzheimer’s Association.

The Alzheimer’s Association was founded in 1980 by J. Stone in collaboration with the National Institute on Aging (Alzheimer’s Association, 2015). The Alzheimer’s Association is a voluntary health organization specialized in Alzheimer’s care, support, and research. With a mission to eliminate Alzheimer’s disease through advancement of research and to reduce the risk of dementia through the brain health promotion program, the Alzheimer’s Association provides face-to face support groups and educational sessions in communities nationwide. The association connects people across the globe using online resources. “The Alzheimer’s Association works on a global, national, and

local level to enhance care and support for all those affected by Alzheimer's and other dementias" (Alzheimer's Association, 2015, p. 1).

According to the Alzheimer's Association (2012a):

The term 'African American' refers to people having origins in any of the Black race groups of Africa, as well as people of African descent from Caribbean Islands and parts of South American, each one of these groups have distinct social and cultural identities. (para. 1)

Thirteen percent of the United States population is African American (AA), of which 2.7% are 65 years and older. It is projected that by the year 2050, 8.6 million African Americans will be 65 years and older (Alzheimer's Association, 2012a). It is suspected that vascular disease is a trigger for Alzheimer's disease. This correlation is supported by prior research studies involving patients with high cholesterol and high blood pressure. Older African Americans are affected at an alarming rate with Alzheimer's disease; they have a higher rate of type 2 diabetes and hypertension in the United States (Alzheimer's Association, 2012a).

To alleviate the severity of the problem of Alzheimer's disease within the African American population, the Alzheimer's Association proposed that more research should be conducted to fully understand the impact and relationship between Alzheimer's disease and vascular dementia. The Alzheimer's Association (2012b) issued a call-to-action to health care professionals and researchers:

1. To accelerate the research to understanding Alzheimer's disease in African and to develop effective methods to manage and prevent disease

2. To increase awareness of Alzheimer's among African-Africans, to expand their participation in research, and to get services and treatment to those who are affected by the disease
3. To develop and expand affordable, culturally appropriate services, including assessment, diagnosis, and care. (p. 1)

According to the Alzheimer's Association, the cause of Alzheimer's disease is attributed to environmental, genetic, and familial risk factors. Apart from age being a key risk factor in AD, the prevalence rate of AD is from 14% to nearly 100% higher in African Americans than in their Caucasian counterparts. The number is expected to rise in the next 30 years (Alzheimer's Association, 2012b). This discrepancy in prevalence could be due to the fact that AA are almost always underrepresented in clinical studies; they often are diagnosed later in the process of diseases, and the screening and assessment tools are usually ethnically and culturally biased (Alzheimer's Association, 2012a). All of the above-mentioned issues cause great financial, emotional, and personal burden to the patients and their communities.

This study focused on Haitians who are experiencing or have experienced mild cognitive impairment. Nursing has conceptualized the need to address delivery of care practices from a transcultural global perspective; accordingly, this study addressed MCI from the lived experience of Haitians living in South Florida. Being of Haitian heritage and living in South Florida, this researcher was interested in exploring the perception of MCI among Haitians living in South Florida. The literature was scant about the proposed population; however, the article from Lin et al. (2012) was used to illustrate the severity of MCI and to support the need for this study. Lin et al. explained that the diagnosis of

MCI is confusing for the patients and their families. From the perspective of a foreigner who is not familiar with the cultural norms and customs of the United States, such diagnosis could be even more daunting. Regardless of etiology, MCI negatively affects the well-being of the individual.

Haiti and Its People

Haiti is a small island in the Caribbean Sea that was discovered by Columbus in 1492. Haiti is a part of the Island of Hispaniola, which includes both the Dominican Republic and Haiti. In 1804, Haiti became the first Black republic to have gained its independence from the French (Central Intelligence Agency [CIA], 2015). Haiti has suffered from instability since the slave revolution in 1804. Since 2010, the democratically elected president of Haiti is Michel Martelly who lives in Port-au-Prince, the capital of Haiti. In 2010, a 7.0 earthquake shook Haiti and killed over 300,000 people and left 1.5 million people homeless (CIA, 2015). The CIA (2015) reported the following demographic characteristics: As of July 2015, the population of Haiti was 10,110,019 people, 54.7% of the population is Roman Catholic, while 18% are Protestants, and roughly 80% of the population practice some form of voodoo (see Figures 1 and 2).

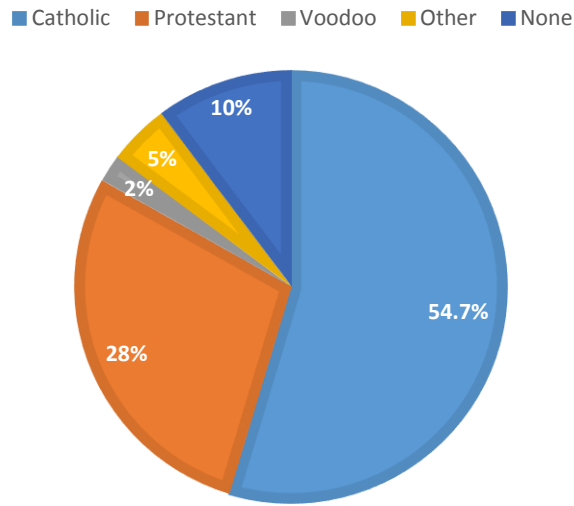


Figure 1. Haitian population demographic: Religious practices in Haiti.

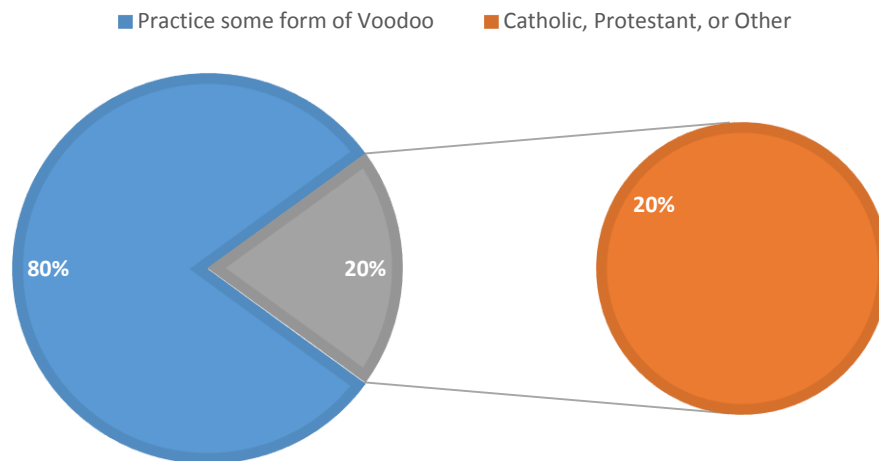


Figure 2. Haitian population demographic: Voodoo and religious practice in Haiti.

The Haitian population age range consists of 33.28% of the population between age 0 and 14 years old; 21.64% between ages 15 and 24; 35.78% between 25 and 54 years old, 5.11% between 55 and 64, and 4.18% over the age of 65 (see Table 1). The total life expectancy at birth is 63.51 years. The literacy rate is 64.3%, with males at 64.3% and females at 57.3% (CIA, 2015).

Table 1

Haitian Population Demographic – Age Ranges in Haiti

Age (Year)	Percentage of population
0-14	33.28%
15-24	21.64%
25-54	35.78%
55-64	5.11%
>65	4.18%

Haiti is considered the poorest country in the Western hemisphere with 80% of people living under the poverty line (CIA, 2015). The 2010 earthquake further damaged the economic system of the island. It is estimated that 40.6% of the people in Haiti are unemployed (CIA, 2015). Haiti produces coffee, mangoes, cocoa, apparel, manufactured commodities, and oils. The country imports foods, manufactured goods, machinery and transport equipment, fuels, and raw materials (CIA, 2015).

Data to objectively describe the people and the island is limited. Very few of the articles located discussed mental health in Haiti; most addressed post-earthquake issues related to mental health (Raviola, Eustache, Oswald, & Belkin, 2012). The oldest book that provided information about mental health in Haiti was written in 1928 by Jean Price-Mars, and it was subsequently translated in 1983. Due to a lack of more recent information, the Central Intelligence Agency web site was found to be a significant source of recent information. The political system of Haiti is in constant turmoil.

The year 2010 is a significant year in Haitian history; it is not only when Haitians democratically elected President Michel Martelly, but it is also the year when they suffered from a monstrous earthquake measuring 7.0 on the Richter scale, which killed 300,000 people and left 1.5 million homeless (CIA, 2015). Following the 2010

earthquake, the Western world acknowledged the health disparities that exist in Haiti regarding mental health services. There were 0.25 physicians for every 1,000 persons in 1998 (CIA, 2015); the World Health Organization (2010) reported that there were 10 psychiatrists and nine psychiatric nurses who are governmental workers in Port-au-Prince; however, more recent statistics could not be located. There are 10 registered nurses for every 1,000 Haitians in Haiti (WHO, 2010). Only 9.4% of the gross domestic product is spent on health care services in Haiti (CIA, 2015).

The way of life in Haiti is a style of *laissez-faire* where clock time is not as important as it is in the Western world, the cultural belief is that the past is important because of the lessons learned, “the present is cherished and savored. The future is predetermined, and God is the only supreme being who can redirect it” (Colin, 2009, p. 171). It is a tradition in Haiti for extended families to live together; the family usually consists of children, husband and wife, and grandparents. In rural areas, the yard called “lakou” is usually the gathering place for the family to socialize (Louis & Hay, 1999). The elderly parents are respected and are cared for at home by their children and relatives (WHO, 2010). “Family, community, and spirituality (religious and otherwise) play integral roles in Haitian norms and practices—including those related to counseling and mental health” (Nicolas, Jean-Jacques, Wheatley, 2012, p. 510). Haitians are very hard-working people; they work in the gardens, care for children, and work in the household and the community. Today, in Haiti, Haitians continue to live in similar ways as their African ancestors used to live.

Health and illnesses. In Haiti, good health is considered to be the ability to achieve internal equilibrium, which is the balance between hot and cold illnesses.

Examples of hot illnesses would be fever or pregnancy, which would be treated with hot remedies versus cold illness such as menstrual cramps, common cold, and arthritis, which would be treated to keep the body warm to balance equilibrium. To be healthy, an individual must be strong, have good color, be plump, and be free of pain. Illness is usually perceived as punishment or considered as an insult on the body (Colin, 2009). Generally, illness is considered to be natural or supernatural; natural illnesses are considered to be short-term illnesses, and supernatural illnesses are considered to be caused by angry spirits (Colin, 2009).

According to Colin (2009), most Haitians prefer to self-treat at first versus seeking health care. Haitians respect health care professionals such as physicians and nurses; most Haitians are polite, shy, and affectionate traditionally; they do not make eye contact during conversation since it is considered to be impolite (Colin, 2009). In Haiti, illness and health-seeking behaviors are influenced by location, religion, and social class (WHO, 2010). Good health is considered as the ability to achieve internal equilibrium, which is the balance between hot and cold illnesses (Colin, 2009; WHO, 2010).

According to the CIA (2015), currently there are 1.3 hospital beds per 1,000 Haitians in Haiti. Haitians suffer from many chronic and acute illnesses comparable to other Caribbean nations. Among the most common physical illnesses are hypertension, diabetes, hyperlipidemia, obesity, and chronic pain. Malaria, dengue fever, and tuberculosis are endemic in Haiti, and HIV/AIDS infection is common (Farmer, 2013; Madrigal, 2006; Marcelin, McCoy, & DiClemente, 2006; Partners in Health [PIH], 2015a). After the earthquake, cholera became prevalent to the Haitian population. Close to 70,000 Haitians have been living in camp-like environments since the earthquake.

Major infectious disease risk is high secondary to food and waterborne illness such as bacterial and protozoal diarrhea, Hepatitis A and E, and typhoid fever (CIA, 2015).

Mild cognitive impairment falls under the umbrella of mental illness since there is not an accepted term used for MCI in Haiti other than “tet pa la” (i.e., memory problem). Mental illness is viewed as an effect from a supernatural force (Colin, 2009). Cianelli et al. (2013) explained that some cultural mental health perspective might not be synchronized with the rest of the Western world; for example, depression and anxiety might be viewed by the believer as a form of punishment (Cianelli et al., 2013; WHO, 2010). Mental health issues are now surfacing since the humanitarian workers and non-governmental organizations (NGO) started noticing the mental health disparity.

Mental health. Louis Price-Mars, who was a pioneer psychiatrist, and Chavannes Douyon were the Fathers of Psychology in Haiti (Boursiquot, 2001). They both worked on culture, psychology, and psychological testing in Haiti to prevent and treat mental illness. Price-Mars introduced major changes in mental health practices. In 1941, Price-Mars founded the Ligue Nationale d'Hygiene Mentale, an institute in Haiti. The institute was a proposal to promote mental health in Haiti. He introduced diagnostic classification of patients at the hospital and changed the barbaric practices that were common in Haiti (Boursiquot, 2001). Price-Mars studied medicine, mental health and illnesses, and the culture in France; he practiced in Haiti. Mental health care in Haiti was scarce and available only to a small private section. Religious leaders provided emotional support and mental health care services to the mentally ill in most rural areas (Farmer, 2013; Nicolas et al., 2012; PIH, 2015b). The most common types of mental disorders are

depression, anxiety, psychosis, and stress in addition to post-traumatic stress disorder (PTSD) related to the 2010 earthquake (PIH, 2015b).

Since the devastating 2010 earthquake, one of the champion of global health and humanitarian services Partners in Health (Zanmi Lasante) has provided mental health care to thousands of Haitians who were affected with post-traumatic stress disorders and other mental health disorders (PIH, 2015b). It is reported by PIH (2015a) that PIH has 50 social workers, 2 public psychiatrists, and 13 psychologists in 12 clinics across the Central Plateau of Haiti. The specific number mental health clinics or hospitals that are operating in Haiti is not reported; however, currently there are many organizations such PIH, University of Miami, CapraCare, and William James College that have community-based mental health services operating in Haiti. The community-based mental health model of PIH in collaboration with the Ministry of Health received a grant from Canada to continue to expand mental health services across Haiti (PIH, 2015b).

Mental illness, usually considered a curse by most rural Haitians, is stigmatized, and as such, it is not discussed or revealed (Colin, 2009); however, in the aftermath of the January 12, 2010 earthquake in Haiti, mental illnesses were brought to the surface. The literature reports of researchers (Desir, 2015; Khoury, Kaiser, Keys, Brewster, & Kohrt, 2012) indicated that Haitians suffer from mental health disorders similar to the rest of the Western world; however, the stigma of mental health has created a significant health disparity regarding mental health in Haiti. Khoury et al. (2012) wrote that evidence of this lack of overall basic health care is due to socioeconomic status, culture, and poor infrastructure of the health care system in Haiti. The information gathered in a study by

Khoury et al. might inform nursing practice regarding MCI in Haitians, and it might give this small segment of the population a voice to express their perspective on MCI.

Voodoo. It is an indigenous belief of most Haitians that mental illness is associated with sorcery and superstition (Lafalaise, 2002; WHO, 2010). Voodoo is a religion of a mixture of African tradition and Roman Catholic practices; it is not practiced by all Haitians, but the influences of voodoo are present in the culture (Farmer, 2013; Khoury et al., 2012; Louis & Hay, 1999). It is a common belief in rural Haiti that some mental illnesses are best treated by voodoo priest or herbal doctors. The researchers hypothesized that this concept might hinder health-seeking behaviors from a biomedical framework (Khoury et al., 2012).

In Haiti, a person views himself or herself as part of the universe. The person is viewed as the center of the universe; therefore, health is considered as a state of well-being connected to the environment (Cianelli et al., 2013). Family, community, and spirituality play a large role into the daily life and health practices of Haitians (Colin, 2009; Khoury et al., 2012; Nicolas et al., 2012). In Haiti, mental health is viewed differently than in the United States. According to Khoury et al. (2012), “the care seeking behaviors of Haitians is influenced by the voodoo worldview” (p. 516). Khoury et al. continued to explain that there is a distinction in Haiti between natural and supernatural illness; consequently, mental health is viewed as a supernatural illness by most rural Haitians.

Language. In this inquiry, the Creole language was used to obtain information since it was anticipated that almost 100% of the participants would be able to communicate in Creole to describe their lived experiences with MCI. Language has long

been used as economic and political tool to manage certain people around the world (DeGraff, 2015a). In Haiti, the language is used as a tool for exclusion, it is used to create and transmit inequities (DeGraff, 2015a). When Columbus arrived on the island of Hispaniola in 1492, Haiti was inhabited by indigenous people who Columbus called Indians since he believed he reached India. Shortly after the arrival of the Europeans, the Indians were exterminated. To continue the search for gold, the Europeans brought slaves from different regions of Africa to Hispaniola (DeGraff, 2015a). Over the years, since all of the slaves did not speak the same languages, they developed the Creole language to communicate. The Creole (Kreyol in Haiti) language has a compilation of Spanish, French, English, and many African languages.

Today, the official languages of Haiti are both French and Creole (CIA, 2015; Colin, 2009). Michel DeGraff (2015a), a professor of Linguistics at Massachusetts Institute of Technology (MIT) and the Founder of the Haitian Creole Academy, explicated the possible association of mental health problems with the lack of mother tongue for security. He explained that language is associated with esteem and if an individual does not have a true identity of language, some mental illnesses could result. Speaking of the success of his initiative to incorporate Creole and technology as two essential ingredients of education, DeGraff (2015a) wrote, “The success of this initiative to date suggests that Kreyol is indeed a full-fledged language which unlimited capacity to express any level of complex thought as in STEM” (p. 11). Although the education system in Haiti is in French, 80% of the population communicates only in Kreyol because 80% of the people are illiterate (Colin, 2009); however, Haitians value education even though they cannot afford it. Most Haitians do not have access to school; plus, only 15%

are privileged enough to afford formal education. Unfortunately, the French language has been used as a tool to delineate the social class struggle. The Haitians who speak French use it as an oppressive tool to control the poor and disenfranchised who do not speak French or who are uneducated. Most commerce and the government operate in the French language (Colin, 2009; DeGraff, 2015a). DeGraff (2015b) wrote:

The *de facto* status of Kreyòl as Haiti's sole national language and as a unifying factor across all social classes is a robust fact and a linguistic asset. As for French, only the upper social classes, some three to five percent, speak it at home on any regular basis. Given these facts, plus what we know about the role of the native language in education, Kreyòl stands at the ready to be used as a powerful tool for nation building and economic development. Yet, there's a widespread entrenched belief that those who speak Kreyòl only are somewhat deficient, that Kreyòl is a lesser language, a language that CANNOT be used for science, for math, for the law, in written press, and so on. (p. 9)

There has been a consensus that Creole should be the primary language for all Haitians; this initiative is underway (DeGraff, 2015a).

Haitians in South Florida

In the United States, some Haitians continue to live to some extent in the same manner as in Haiti. They live close together and gather in the afternoons or on the weekends to socialize. Usually, the household consists of parents, children, and grandparents. While abroad, Haitians keep close contact with their friends and family in Haiti through phones and the World Wide Web. Food is relished and is viewed as a

cultural treasure so “most Haitians retain their food habits and practices after emigrating” (Colin, 2009, p. 175).

None of the articles reviewed discussed MCI of Haitians in the United States. Haitians migrated to the United States since the 1900s; however, the biggest influx occurred in South Florida after the dictator Duvalier proclaimed the presidency-for-life in 1964 (Colin, 2009). Haitian immigrants were known as “boat people” because they arrived to the shores of America on small sailboats to escape extreme poverty (Colin, 2009). Today, there are about 252,000 Haitians in Florida. Florida holds the largest number of Haitians born in Haiti; the hub of the Haitian cluster is called Little Haiti in Miami, Florida (City-data.com, 2015). It is presumed that they continue the same cultural health perception as in the homeland.

This study attempted to understand the lived experiences of Haitians with MCI in South Florida. Douyon, Marcelin, Jean-Gilles, and Page (2005) explained the following: Haitians in Miami have had the misfortune of encountering some of the most daunting barriers ever presented to an immigrant group. Not only have some of them made the trip to South Florida in the flimsiest of craft through dangerous seas, but many have sojourned for months or years under hostile conditions in the Bahamas before finally making their way to Miami. Once on the shore in Dade County, the new arrivals have faced a community that that has routinely ghettoized populations of color during most of its existence. Urbanized areas have well-defined zones inhabited by people of African descent whether they are North American, Bahamians, Jamaicans, or other Caribbean. (p. 116)

The Haitian group in Miami was recognized for its size and cohesion around 1982, only to be further marginalized for its supposed linkage to HIV/AIDS, tuberculosis, superstition, and juvenile crime. Later analysis of the disease process of HIV/AIDS revealed that Haitians were not major conduits of HIV/AIDS, but the damage to their reputation was already done. Unemployment, underemployment, and poverty persist among the population in South Florida (Douyon et al., 2005).

Unlike Haiti, the United States has a robust health care system including mental health services, yet mental health research studies, particularly those analyzing MCI within the Black population, are scarce. While health care practitioners and the biomedical systems are well respected, Haitians usually simultaneously use both traditional remedies and Western medicine. Typically, Haitians will attempt treatment of illnesses at home then they will turn to spiritual care; if unsuccessful, then they will turn to Western medicine as last resort. Medications are usually shared, and the individuals seek Western medicine when they are very sick (Colin, 2009). These health practices make the Haitian population an interesting group of people to conduct research studies. A large group of marginalized African Americans and people of African descent live in Miami Dade County (Douyon et al., 2005); therefore, from a researcher's perspective, the region has many potential research participants. For the purpose of this study, the term Haitians in South Florida encompassed all individuals with Haitian heritage.

Statement of the Problem

Mild cognitive impairment is an acquired syndrome that is an especially troublesome impairment to diagnose because it is usually viewed as a period between normal functioning of the older person's brain and dementia (Feldman & Jacova, 2005).

Mild cognitive impairment could hinder the quality of life of the person because of the uncertainty associated with the diagnosis and the protracted time it may take to arrive at a definite diagnosis. Furthermore, if the MCI is not resolved, it could eventually turn into dementia, most commonly Alzheimer's disease (Lin et al., 2012). Mild cognitive impairment could be the precursor to a tumor, or it could also be related to anxiety, severe cognitive impairment, or a mood disorder. This memory deficit experienced by the person could cause difficulties with the daily life of the individual where ordinary tasks such as cooking, driving, keeping appointments, or taking important medications are severely compromised.

With MCI, some functional decline such as weakness or gait instability could be present, which could cause loss of independence and autonomy. The individual might exhibit some new or different behaviors than usual. This new status might not be understood by both the individual and/or the family members, which might create even further challenges and misunderstanding. The syndrome of MCI might cause severe financial burden associated with care and treatment. The ambiguity of the diagnosis might be even more frightening and difficult to understand and to manage from the cultural perspective of Haitians or any non-Western nation, where the perception of illness is based on natural and supernatural nuances of health.

Purpose of the Study

The purpose of this qualitative phenomenological inquiry was to explore the meaning, structure, and essence of the lived experience of Haitians living with MCI in South Florida. This inquiry aimed to give those affected Haitians a voice to express their experiences with MCI, and it might provide a greater understanding and description of

the essence of their experience regarding MCI. Additionally, the aim of the inquiry was “to construct an animating, evocative description of human actions, behaviors, intentions, and experiences as we meet them in the life world” (van Manen, 1990, p. 19).

“Developing a clearer understanding of Haitians’ beliefs about this phenomenon may assist in providing culturally effective treatment for this population” (Nicolas et al., 2012, p. 511).

Research Question

The overarching question that guided this inquiry was: What is the lived experience of Haitians who are living in South Florida who have mild cognitive impairment?

Philosophical Underpinnings

Paradigm, also known as worldview, is defined by Thomas Kuhn (1996) as a discipline’s specific method of solving a puzzle, viewing human experience, and structuring reality. Kuhn (1996) wrote that “scientific knowledge, like language, is intrinsically the common property of a group or else nothing at all. To understand it we shall need to know the special characteristic of the groups that create and use it” (p. 210). Interpretivism is the paradigm that was used to guide this inquiry. Through interactions between the researcher and the participants, ideas are generated and at times ideas are interpreted. The researcher inductively develops theory or pattern of meaning based on the approach chosen for the inquiry (Creswell, 2013). The research questions, as opposed to interview questions, are broad, general, and open ended to allow the participant to construct the meaning of the situation. The researcher interprets or makes sense of the meanings the participants attain about the world; therefore, the social constructivist

approach is often referred to as *interpretive research* (Creswell, 2013). The goal of interpretative research is to understand the lived experience of the person. The purpose of interpretive research is to understand and give definition and meanings to the phenomenon (Lincoln & Guba, 1994). The participants of interpretative philosophical framework are usually underrepresented or marginalized groups (Creswell, 2013).

Social constructivism is grounded in an interpretive philosophical framework. The goal of social constructivism is to understand human experience (Creswell, 2013). Constructivist views are directly reflected in phenomenological approach. Social constructivism means the person is seeking to understand the world in which he or she lives and works. During qualitative research, the researcher relies on the participants' views of the situation.

Qualitative Inquiry

Qualitative research is aimed at understanding a phenomenon or exploring attitudes. It provides crucial information about why a particular phenomenon happened instead of how it happened as in quantitative research. The central aim of qualitative research is to understand the meaning of experiences of other people. In addition, qualitative research is used to understand how individuals are experiencing what they have been confronted with, both positive and negative. The researcher can use the individual's own words to describe his or her perspective of a phenomenon (Creswell, 2013). Many types of qualitative research approaches exist, including phenomenology, ethnography, grounded theory, narrative inquiry, case study, life history, and historical method. The researcher chooses the approaches that would best fit to assist him or her in formulating the problem and to state and answer the question of the phenomenon of

interest (Creswell, 2013). The participant's world becomes visible through qualitative research. Qualitative research has several characteristics (Creswell, 2013):

1. It occurs the natural setting of the participants.
2. The researcher is the key instrument in the study. Data are collected by the researcher. The researcher observes behaviors and interviews the participants.
3. Multiple methods are used to gather information. The researcher uses interviewing methods, direct observation of participants, and documents to form data. The researcher interprets the data and organizes it. Themes or categories are identified by the researcher.
4. Inductive and deductive logics are used to assist with reasoning. Patterns, categories, and themes are organized inductively to create an abstract unit of measurement. Deductive logic is built from the themes collected by the researcher.
5. The researcher learns the participants' meaning of the phenomenon. The main reason of qualitative inquiry is to learn the meaning of the experience from the participants' perspective so the focus remains on the views of the participants.
6. The research process is an emergent design. All phases of the process could be altered to capture the lived experience of the participants. For example, the research interview questions or the site of data collection could be changed based on the research approach being used.

7. Reflexivity means the researcher positions himself or herself to divulge how his or her background, work and cultural experiences, and history might influence the study. The researcher reveals what he or she intends to gain from the study.
8. The researcher develops a general picture of the phenomenon based on the data collected. The complex interactions among factors are identified to create a holistic account of the phenomenon of interest. It does not establish cause and effect (pp. 45-47).

Qualitative research is used to explore, to empower individuals, to develop theories, to explain, and to understand the phenomena of interest. Qualitative inquiry recognizes that individual values are honored, and these values are negotiated among individuals. It asserts that reality is co-constructed between the researcher and the researched and is shaped by individual experiences. Multiple realities are constructed through lived experiences and interactions with others (Creswell, 2013; Munhall, 1994; van Manen, 2014). In the process of a qualitative inquiry, data collection is performed in the natural setting and is sensitive to people and places under the study. Data analysis is both inductive and deductive and establishes patterns or themes, and the final presentation report or writing includes the voice of the participants, description and interpretation of problem, reflexivity of the researcher, contribution to literature, or a call for change (Creswell 2013; Munhall, 1994; van Manen, 2014). Qualitative research requires “extensive time in the field” (Creswell, 2013, p. 49), engagement in complex time-consuming data analysis, and extensive writing process of passages to demonstrate verbatim wording of participants to establish rigor (Creswell, 2013).

The five philosophical assumptions of qualitative research are ontological, epistemological, axiological, rhetorical, and methodological (Munhall, 1994).

Ontological refers to “the nature of reality and its characteristics” (Creswell, 2013, p. 20).

Ontological assumptions state that multiple realities exist through the viewpoint of the individuals who are experiencing the phenomenon. The Haitian participants might view MCI differently based on their cultural perspective; therefore, their reality of MCI might differ from that of other cultural groups.

Epistemological assumptions question “what counts as knowledge” (Creswell, 2013, p. 20); they attempt to justify knowledge and to clarify the relationship between the researcher and the person who is being researched. Epistemology obtains subjective information from the participants and uses quotes from participants to illustrate rigor. The researcher spends time with the participants in the field. This qualitative research assumption requires the researcher to get as close as possible to the participants. Knowledge is gained from the subjective experiences of the participants. Once interviewed and contextualized, the Haitians’ knowledge of what is it like to have experienced MCI should surface.

Axiological assumptions refer to the role of values in the study. The researcher admits that biases could be present, that research is value laden, and that the researcher’s and the participants’ values might be reflected. With axiological assumptions, it is assumed that the cultural values of the Haitians will prevail and will be reflected in the results. The mental health cultural values might be reflected in this study from the experiences of the participants. Cultural values influence the health care needs of individuals in various cultural groups (Colin, 2009).

Rhetorical assumptions mean to explore what is the most appropriate language and what is the voice to be used in reporting the results of inquiry (Creswell, 2013). Rhetorical assumptions was employed by reflecting the verbatim wording of the participants from the interview; however, while reporting the results of the study, the researcher needs to present it in the language of the target audience or reader. Since this researcher is attempting to describe the common meaning of a group of people and their lived experiences of a phenomenon, phenomenology is the best philosophical approach to use since “phenomenologists focus on describing what all participants have in common as they experience a phenomenon” (Creswell, 2013, p. 76). The meaning of the lived experiences of Haitians will be written verbatim and translated into the English language so that the readers of the inquiry would understand the exact meaning of the participants’ reflections.

Finally, methodological assumptions refer to the process of research; they question “what is the language of research?” (Creswell, 2013, p. 20). Inductive logic is used to study and examine the topic at hand within its context, and it uses the best research design for data collection and analysis. Methodological assumptions through phenomenological research help to determine the essence and to uncover the meaning of MCI of Haitians in South Florida. It is not unusual for the researcher to change certain interview questions during the research interviews, which is done based on the method that is being used to collect data and analyze data. For the purpose of this study, phenomenology will be used as both a philosophical framework and a research method to collect and analyze the data in this inquiry.

Phenomenology

Phenomenology, both a philosophy and a method, is often considered central to the interpretive paradigm. Phenomenology is popular in the social and health sciences, as well as sociology, psychology, nursing, and education. A phenomenological research approach will guide this inquiry. The purpose of this qualitative phenomenological study will be to understand essence of the lived experiences of Haitians with MCI in South Florida. Phenomenology explores the essence of the experience; it aims for a deeper understanding of everyday life and studies the individual's lifeworld (Munhall, 2012). Phenomenology will eventually construct meaning of the phenomenon studied; it believes that there are multiple realities (Creswell, 2013). Moreover, it seeks to not only understand but to provide explanation of the phenomenon; it uses a phenomenological approach to understand and interpret the lived experiences of the individual.

Phenomenology was created by Edmund Husserl, a German philosopher. Husserl introduced phenomenology during the mid-1890s. Husserl and his student Martin Heidegger promoted phenomenology; they explored the "lifeworld" and focused on "essences" of the experience. Martin Heidegger believed that interpreting of meanings is influenced by cultures, history, and worldviews. The phenomenology of Heidegger was improved by the works of Sartre and Merleau-Ponty, Moustakas, and van Manen (Munhall, 2010). Additionally, Colaizzi, Giorgi, and van Kaam have contributed to the development of phenomenology (Munhall, 1994). Phenomenological inquiry attempts to understand meaning experiential or spiritual (Creswell, 2013; van Manen, 2014). Munhall (1994) explained that studying the lived experience of the person is the same as

the study of *being*. From the research perspective, this research is attempting to understand the being experience of Haitians with MCI (Munhall, 1994).

Husserl is considered the father of phenomenology. Heidegger continued the movement and emphasized the being-in-the-world part of phenomenology (Munhall, 1994). As stated earlier, phenomenology explores the lived experiences of all of the persons involved with the phenomenon. Phenomenology is not saturated with presuppositions; epoché is used when researchers wish to set their preconceived ideas apart to enable them to be able to analyze the data with a fresh view (Creswell, 2013). Transferability, dependability, confirmability, and authenticity are used to establish trustworthiness and rigor of the inquiry (trustworthiness will be fully developed in the methodology section) (Lincoln & Guba, 1994).

Phenomenology is chosen for this study because of the merits of this qualitative approach. It is grounded in a social constructivist view, and the attempt of qualitative research is to give value or to appreciate the phenomenon that the participants are describing. Phenomenology is used “to describe the essence of the lived phenomenon” (Creswell, 2013, p. 76). The focus on lifeworlds is important because they include emotions, motivations, symbols and meaning, empathy, and other subjective aspects associated with natural life experiences of individuals or groups (Berg, 2012, p. 15). Van Manen (1990) defined lifeworlds as spatiality, temporality, corporeality, and relationality; these four existential lifeworlds help to guide reflection during the research process.

Spatiality means environment or our space; it is intended to look at the lived environment of the Haitian to understand their viewpoint. Corporeality, which refers to the embodiment of the body we inhabit, will guide the reflection of how the participants

view illness and health issues. This lifeworld dimension refers to the unification of body and mind. Max van Manen (1990) defined temporality as the time we are living. This lifeworld will guide the researcher in understanding the participants' sense of time occupation. It will assist the researcher to the "lived time" of the Haitians with MCI; temporality involves history of the lived experience. Finally, relationality refers to our world in relation to others and how we see ourselves and others (van Manen, 1990). The lived relationship between Haitians might be clarified through this lifeworld. Van Manen indicated that the lifeworlds are productive categories for the process of posing, reflecting on, and writing phenomenological questions. These lifeworlds will assist the researcher to give meaning to the experience of Haitians with MCI.

Phenomenology attempts to find the truth of lived experience; it is a process of learning and constructing the meaning of human experience through intensive dialogue with persons who are living the experience. Hermeneutic is defined as reflection on experience using language and sensitive interpretive devices to convey a certain phenomenon (van Manen, 2014). The "aim of phenomenology is to grasp the exclusively singular aspects (identity/essence/otherness) of a phenomenon or event" (van Manen, 2014, p. 27). It views the person as a whole entity and not as a sum of the parts. Meaning is contextually constructed as an intersubjective phenomenon (van Manen, 2014). Meaning of the lived experience is constructed in the transaction.

Phenomenology recognizes that the world and its people are constantly changing and evolving, which creates a dynamic reality (Munhall, 1994). The researcher uses textual description to explain what happened and structural meanings to explain how the phenomenon was experienced. Epoché or bracketing is used in an effort to reduce biases

of the research from the study (Munhall, 1994). Phenomenology aims to disclose lived experience through perception. Perception is the original awareness of what an individual lives through during an experience. There are no preconceived notions, expectations, or frameworks present to guide the researchers as they gather or analyze information from inquiries. Phenomenology believes that there are no assumptions made prior to the study. The researcher approaches participants and the experience with an open mind. During the data collection phase, whatever the participant communicated is valid whether the researcher agrees with the statement (Creswell, 2013; Munhall, 1994, 2012). A person is viewed as unique and has the potential and experience opportunity for change.

The two main types of phenomenology, descriptive and interpretive, will be briefly discussed to better accentuate the researcher's choice of approach. Descriptive phenomenology is based on Husserl's approach. Husserl believed the researcher must bracket all attitudes to accurately represent the individual in the phenomenon of interest. He believed the researcher can exclude his or her feelings from the research experiences of the individual (Munhall, 1994). Whereas Martin Heidegger believed that researchers cannot fully bracket our ideas and perception of the world around us, Heidegger believed in interpretive phenomenology, which indicated that individuals can use reflection as a tool to acknowledge their own feelings to better understand the feelings of others. Heidegger introduced the hermeneutic circle to replace bracketing. Both Merleau-Ponty and Heidegger felt that people are interrelated in their worlds and that through engagements, they learn about themselves and others (Munhall, 1994).

Max van Manen believes in hermeneutic interpretative phenomenology, which is a combination of both description and interpretative phenomenology. With hermeneutic interpretative phenomenology, both the researcher and the participants achieve a deeper understanding and assign meaning to the phenomenon of interest. To comprehend what it means to be in the world, van Manen recommends using description, interpretation, language, and activities to understand the essence and meaning of the lived experience of the individual (Munhall, 1994; van Manen, 2014). During hermeneutic interpretative phenomenology, the researcher must investigate the phenomenon through interviews. He or she must bracket preconceived ideas before and after the interviews through reflections and journaling, which emancipates the researcher to be opened to the ideas of the participants. Writing, rewriting, member checking, and reflecting are completed throughout the inquiry. The data will then be given meaning where a deeper and richer understanding of the phenomenon of interest will be obtained (Munhall, 1994; van Manen, 2014).

Phenomenological Assumptions

Phenomenology involves going back to the roots of knowledge; it is a search for wisdom. There are four main assumptions for phenomenology as described by Munhall (1994): The first assumption is intentionality of consciousness; consciousness means life itself. This assumption explains that the reality of an object is inextricably related to an individual's consciousness of it. It involves sensory awareness of something or the responses of the awareness to the environment. It involves the perception of an object. Regarding the MCI phenomenon, some participants might believe that the impairment in cognition is related to the normal aging process, while others have different perception of

what is happening to them. The researcher will engage the participants in a conversation so that perhaps they will want to explicate their encounters with MCI.

The second assumption is embodiment, which refers to the awareness of us being-in-the-world (Munhall, 1994). It states that we use the body to get perspective of our senses. As stated previously, Haitians believe in hot and cold illnesses, which means that we use the body to react to illnesses or conditions. This perception is congruent with the philosophical framework of phenomenology. It is expected that through the use of phenomenology, this researcher will obtain a rich and deep understanding of MCI from the Haitian perspective. The third assumption is natural attitude, which involves interpreted experiences; it helps in understanding responses to change (Munhall, 1994). The Haitians in South Florida are being studied to explore and understand their cultural views of MCI or on mental health issues while in the United States versus the views and perceptions of Haitians in Haiti on mental health issues. The fourth assumption is experience and perception, which is referred to as the “original modes of consciousness,” and perception varies from each person (Munhall, 1994). It asserts that truth is not as important as what is perceived. Perception and experience might determine the responses of the participants regardless of location or disease process. This research inquiry will explore the perceived realities of those Haitians affected with MCI.

These four phenomenological assumptions are the concepts that assist researchers using phenomenology to explore and understand the meaning of the lived experiences of individuals or groups of individuals (Munhall, 1994). These assumptions are vital to understanding the lived experience since an individual’s consciousness gives meaning to reality. Phenomenology describes the whole context of the individual and his or her

circumstances (Munhall, 1994). Phenomenology as explained by van Manen is the best approach to give an understanding of the lived experience of Haitians who have been diagnosed with MCI and are living in South Florida.

Max van Manen's Phenomenology

Max van Manen is a Canadian social scientist and an educational philosopher. He advocates for conducting human science research to enlighten and to improve pedagogy. Van Manen (1990) developed a phenomenological philosophy using elements of both Husserl's and Heidegger's philosophies and merged both hermeneutic and descriptive phenomenology. This approach is both descriptive and interpretive. Using hermeneutic phenomenology, the researcher seeks to uncover the meanings in everyday existence and what is "the fulfillment of our human nature: to become more fully who we are" (van Manen, 2014, p. 28). Interpretative hermeneutic allows that the researcher to obtain deep, descriptive data and give meaning to the experience.

Hermeneutic phenomenology is concerned with research about the lived experience of a group of individual and the interpretation of it. It is used to uncover the meaning of everyday life. Several approaches to phenomenology exist. Van Manen combined hermeneutic and phenomenology and developed six steps to understand the lived experience of the individual. This conception of phenomenology drew ideas from philosophy, psychology, and education (Creswell, 2013). In 1990, van Manen named six research activities for reflecting and interpreting the phenomenon: (a) turning to the nature of lived experience, (b) investigating experience as we live it, (c) reflecting on essential themes, (d) describing the phenomenon through the art of writing and re-writing, (e) maintaining a strong and oriented relation to lived experience, and (f)

balancing the research context by considering parts and whole (Munhall, 1994; van Manen, 2014). The six steps are not sequential, but they are interconnected. Phenomenology attempts to get access into the lifeworlds (Munhall, 1994); it experiences, but it does not conceptualize.

Significance of the Study

This study was significant given the lack of data regarding MCI in the Haitian community. In the United States, data about the Haitian experience is nonexistent since illness experiences are integrated with the experience of African-Americans. This study specifically addressed the lived experiences of Haitian in the United States; consequently, the data obtained from the study provided a greater understanding of MCI in an ethnic community. A better understand of the MCI might contribute to better quality of life for future Haitian cohorts.

Significance to Nursing

Nursing as a profession needs to continue to add to its repertoire of scholarly inquiry to keep abreast in the profession. Studying the lived experience of the person with MCI accorded health care professionals an advantage in offering better care for the patients and in anticipating the needs of the patients and their families. The results of this study provided evidence-based data regarding the perception of the population affected and nursing care. Using a phenomenological approach, this study attempted to describe the common meaning of the lived experience of many individuals at the same time; in this case, the phenomenon is MCI (Creswell, 2013). Nurses could use this scientific data to develop and implement nursing care for the person with MCI.

Investigating MCI from a nursing perspective is integral to the success of the nurse-patient interaction. A nursing intervention will not succeed if the nurse is not culturally competent to meet the needs and cultural relevancy of the client's health care necessities. It is important for the nurse to understand MCI from the cultural perspective of Haitians because most cultures are different in health care practices. One example from a Haitian cultural perspective regarding hot and cold illnesses is an upper respiratory infection—the individual will insist on tying his or her head with a scarf to prevent cold exposure to the scalp for healing to take place. In this instance, the nature and meaning of the malaise is important in the healing process. The client might not comply with a specific recommendation from the nurse or health care provider because the client might feel such a recommendation is wrong and not conducive to healing.

Additionally, the results of this inquiry could lead to improvement in quality of care. The results could also address certain health issues associated with MCI that may be resolved swiftly and efficiently without duress to patient, caregivers, or health care professionals. The data obtained may increase nursing knowledge and could advance the science of nursing.

Implications to Nursing Education

The results of this study could guide nursing curriculum development. As discussed by Colin (2009), culture influences the health care needs of individuals in various cultural groups; therefore, to reduce the disparity in the health care field, a cultural competency course might need to be included in the nursing curriculum. Understanding the perspective of the Haitians with the disease should enable nursing faculty to ensure that the curriculum addresses health and illnesses of an ethnically

diverse patient population and their caregivers. As suggested by Madeline Leininger, culturally based care is essential to any individual's health since culture plays an integral part in the health and well-being of individuals. This cultural integration is essential for a successful health care outcome (as cited in Welch et al., 1998).

Implications to Nursing Practice

Understanding the perspective of the person diagnosed with MCI could enhance health care in any setting such as an acute care environment, physical therapy, surgery, and mental health settings. The quality of life of the patients might be positively affected since the health practitioner might have a richer understanding of MCI from the individual's cultural perspective. Therefore, cultural competency is essential to understand the community to provide effective care. The stigma of mental illness could deter the individual from seeking or accepting health care services. Understanding the culture may help the nurse to develop better interventions to meet that population's needs. Patient care outcome might be more positive if the nurse is culturally aware and sensitive.

Implications to Research

The Haitian population in Florida is the largest outside of Haiti. Little research has been conducted regarding mental health of this population. Research addressing the needs of this large group is of paramount importance to ensure the well-being of this entire population. Furthermore, more research is needed involving patients who are marginalized and those who are from different ethnic heritage and perceptions. "Haiti has the lowest rate of professional psychological support in the Caribbean and Latin America, and one of the lowest in the world" (James as cited in Nicolas et al., 2012, p.

513). Research involving individuals with MCI from any culture will be beneficial to the health care system as a whole. Findings from the inquiry could provide better ways to develop interventional programs to meet the specific needs of those patients. This nursing research will contribute to the current body of nursing knowledge on mental health issues.

Implications to Health/Public Policy

Outreach programs and specific interventions could be developed based on the findings. Once the lived experience of participants is known, more research could be funded to obtain better insights into mental health problems involving many other cultures. Since mental health problems are most often associated with cultural norms (Khoury et al., 2012), if MCI is understood from the perspective of the individual, then the ethical concerns involving the MCI care issues can be better established and addressed. Nursing care standards and expectations can be developed based on the cultural understanding of the MCI. The results of the study could affect legislation to increase funding to improve the mental health services for the South Florida Haitian population. Even though the study will be conducted in the United States, the results could be used by Haitians health care workers here and health care workers in other countries.

Scope and Limitations of the Study

The scope of this study was conducted on Haitians with MCI residing in South Florida. The limitations of the study included the fact that the participants must live in South Florida only. Due to the nature and stigma associated with mental health illness and memory disorders, the sample size could have been limited. A purposeful sampling

strategy was used; therefore, the participants were referred to the study by health care clinics and from pillars of the community. Since Haitians are more passive and polite, the researcher had to effectively employ therapeutic communication techniques, which helped to develop trust and confidentiality. Another limitation foreseen is the actual diagnosis itself, which could have limited effective communication between the researcher and the participants. The researcher transcribed the data accurately and appropriately stored the data to ensure privacy and trustworthiness. Had the participants refused the member check interview, it would have not been surprising based on the condition of their MCI and cultural passivity. The novitiate of the researcher could have limited the study. The transferability of the study could have been limited secondary to the use of qualitative research.

Chapter Summary

This chapter discussed the introduction to this inquiry. The background information, the purpose of the study, the research question, the philosophical underpinning, and significance of the study were presented. The purpose of this inquiry was to explore the lived experience of Haitians with MCI who are living in South Florida. A qualitative research framework was used to understand the lived experiences of Haitians with MCI who are living in South Florida. During qualitative research, the researcher explores the lived experience of the individual, including how the person thinks, how the person feels, and how the person behaves. Phenomenology explores the essence and meaning of the lived experience of a group of people with a particular phenomenon. With Max van Manen's hermeneutic interpretive phenomenology

approach, both the researcher and the participants achieve a deeper understanding and assign meaning to the phenomenon of interest.

CHAPTER TWO

REVIEW OF THE LITERATURE

The purpose of this qualitative phenomenological inquiry was to explore the meaning, structure, and essence of the lived experience of Haitians with mild cognitive impairment in South Florida. According to Creswell (2013), a literature review is important to identify gaps in the literature and to analyze prior studies. Munhall (2012) suggested that an extensive review of the literature on the experiential description be postponed until after the data collection is completed so that the researcher will not be influenced by the literature review.

A search of relevant literature across disciplines was conducted to explore the phenomenon of mild cognitive impairment, patients' perspective, Haitians with MCI, and Haitians and mental health across all disciplines using ProQuest search engine provided by Barry University's online library. The following computerized databases were used for this search: The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Dissertation Abstracts, Educational Resource Information Center (ERIC), EBSCOhost, Medline, PubMed, OVID, and Science Direct, Health Reference Center-Academic, Medicine, Modern Language Association (MLA), and Periodical Abstracts (PerAbs: Covering literature, religion, psychology, and women studies). The keywords used in the search were mild cognitive impairment, mental health and Haitians, Haitians, perception of mental health and Haitians, attitude and health beliefs and Haitians in South Florida. Language limit was set for English only. No limit was set to territory; therefore, articles were obtained from Europe, Canada, Australia, China, Haiti, and the United States. A limitation was imposed to find literature published since 1983 in order to

adequately capture classic historical publications regarding mental health illnesses in Haiti. The literature search was expanded to include the translated version of the book *So Spoke the Uncle*, which was originally published in 1928.

A random selection process delimited the profusion of theoretical references that were found regarding MCI. Additionally, 12 research studies were reviewed in which the experience of Haitians, mental health, and cultural groups were explored. Synthesis of the literature revealed what is known and not known about MCI and Haitians. This literature search resulted in three main areas for discussion: the historical background of MCI, the issues related to mental health in Haiti, and the issues related to mental health of Haitians and the African American diaspora in South Florida. At the end of this chapter, the researcher's experiential context will be discussed.

Historical Context

Mild Cognitive Impairment

Mental health is defined by the Centers for Disease Control and Prevention (CDC, 2013) as “a state of well-being in which the individual realizes his or her own abilities, can cope with normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (para. 2). Mental illness is defined as “a collection of mental disorders; it ranges from any health condition that alters thinking, mood, or behavior that is concomitant with either distress or both impaired function and distress” (CDC, 2013, para. 3). Mild cognitive impairment as previously stated is defined as a “mild decline in either single or multiple cognitive domains—such as memory, executive functioning, attention, or visuospatial abilities—while global cognition and basic activities of daily living remain intact” (Lin et al., 2012, p. 22). In the United

States, most adults believe that mental health problems can be treated (CDC, 2013). In an effort to treat mental illness in the United States, emotional well-being, psychological well-being, and social well-being are identified as determinants of mental illness. Some of the common mental illnesses include depression, anxiety, psychosis, bipolar disorders, and dementia. It is of paramount importance that nurses protect not only the physical aspects but also the mental health aspects of our aging population. The word well-being is used synonymously with perception and meaning of life or quality of life (CDC, 2013).

As the population ages over 65 years, the problem of impaired cognition develops. Cognitive impairment can range from mild to severe. This cognitive impairment is seen in the syndrome called mild cognitive impairment. Mild cognitive impairment could be caused by multiple reasons such as any dementia most specifically Alzheimer's disease, stroke, traumatic brain injury, infections, post-traumatic stress disorder, depression, vitamin B12 deficiency, or side effects of medications. Therefore, it is understandable that some form of MCI can be treated based on causation while others eventually progress to dementia (CDC, 2013; Lin et al., 2012).

Few research studies about mental health and Haitians exist. Most of the studies reviewed reveal information on Alzheimer's disease (AD) and not MCI. Many studies link both MCI and AD and explored the experiences of the caregivers while caring for people with AD. Most of the studies focus on the perspective of the caregiver concerning the person with Alzheimer's disease; however, research studies are limited in providing the disease experience from the perspective of Haitians with MCI. Many studies have been published that focus on Alzheimer's disease, ranging from the nature of the disease to testing responses of medications, exploring the lived experience of the caregivers of

AD patients in all of the stages from stage one early diagnosis to end-stage. The literature review does not reveal many research studies from the perspective of the patient experiencing Alzheimer's disease. Furthermore, among the studies located, this author was not able to identify one study in the United States or abroad that addressed the lived experience of Haitians with MCI. Various issue-related articles were published regarding issues on MCI and AD. Adamson (2001) wrote "Unfortunately, little attention has been paid to understandings of dementia held by African/Caribbean and South Asian families in the UK" (p. 392). He continued to emphasize that "the carer's understanding of the disease process leads to better care and coping mechanism" (Adamson, 2001, p. 393). One disclaimer that is important to emphasize is that MCI is not a term used in the Haitian Creole vocabulary; such syndrome would be verbally described as opposed to be named as a disease entity. This researcher recognizes the limitation of the lack of literature on MCI. Mild cognitive impairment syndrome will be identified under the umbrella of mental health and illnesses because it will easily be identified and understood from the Haitian cultural worldview.

One vital aspect of conducting research with patients with cognitive impairment is the issue of obtaining proper informed consent. Some patients cannot cognitively give informed consent because of severe memory impairment; for the purpose of this research, only patients with mild cognitive impairment were recruited. Slaughter, Cole, Jennings, and Reimer (2007) explained that some guidelines are created to protect vulnerable patients from exclusion or improper consent. Research ethics boards are usually used to review the ethical merits of the studies. Mast (2009) cautioned that when dealing with the patient with cognitive impairment, individuals must not assume that the patient is not

aware. Nevertheless, many studies have documented that it is extremely important to interview the patient with AD, as highlighted by Beuscher and Grando (2009), who said that researchers need to “give a voice” to the patient with cognitive impairment (p. 8) so they can verbalize their thoughts.

The major fear of most people with MCI is that it might progress to Alzheimer’s disease. Since AD is a debilitating and a progressive disease, it directly affects the quality of life of the individual diagnosed (Benbow & Jolley, 2012). Alzheimer’s disease causes several untoward burdens on the patients and their families; for example, the cost of caring for patients with AD is astronomical for the patient and their families, and it is an economic burden for the health care system (Albert et al., 2011; Gauthier et al., 2006). Individuals with AD might be able to provide insights into their own care (Benbow & Jolley, 2012). Phinney (1998) explained that, “These findings point to the importance of taking into account the patients’ perspective to better understand the experience of living with dementia and develop improved treatment and care practices” (p. 8). The findings might augment nursing knowledge and improve practice in the care of these patients; furthermore, research studies that address the personal experiences of the person with mental health disorders might provide practitioners with information to properly and effectively attend to the challenges associated with the delivery of health care to this population.

The first study in this section was conducted by Kornhuber et al. (2009), and it was a longitudinal study on three sets of patients—some with MCI, some with mild dementia, and a control group. The authors initiated the study after having identified the dramatic increase of older people with dementia and the high prevalence of cognitive

issues, which is causing “a considerable economic impact” (p. 405) on the German population. The German Dementia Competency Network (DCN) wanted to establish standard for treatment and diagnosis of MCI and dementia and prognosis of diagnosis. This large-scale cross-sectional and prospective diagnostic, treatment, and observational study was funded by the Federal Ministry of Research and Education. In addition to diagnostic and laboratory tests, two clinical trials were conducted once the subjects could be selected. Descriptive statistic two-sided *t*-test, non-parametric tests, and calculation of Pearson’s correlations were used to identify and compare patient groups. No specific test was discussed since this is a multiphase study and multiple manuscripts on different aspects of the study were published. SPSS and SAS were used to analyze data.

Clinical trials were conducted to evaluate medication efficacy and safety. The safety and efficacy of combination drugs galantamine and memantine versus galantamine alone were studied. Fourteen German memory clinics associated with hospitals were used to evaluate 2,113 subjects in the study. The participants had to be 50 years and older, fluent in German, and not suffering from substance abuse. Data collection was transferred and kept in a GCP-certified system via the Internet. The data were kept in databanks. The result confirmed early detection procedures for MCI and dementia. The standard for treatment for AD is underway; more recommendations were made for future clinical trials with AD (Kornhuber et al., 2009, p. 404). The results of the clinical trials were not published in this article except that early or predictive diagnoses of dementia were encouraging. The patients with AD were significantly older. The education level was lower in the patients with AD compared to the patients with MCI. A large subset of the patients was found to suffer from MCI as opposed to AD. A relationship existed

between cognitive testing and low Mini Mental Status Exam (MMSE) score and the development of AD in later years.

Weybright et al. (2010) conducted a single subject, multiple baseline 2x2 design study to evaluate the effects of interactive video games on older women with MCI. Two volunteers were obtained from an assisted living facility. One participant, Martha, age 93, scored 21 on the MMSE, and the other, Judy, age 86, scored a 26 on the MMSE. Using observational measures, a single-subject, multiple baseline design compared a television watching phase and interactive video game phase. The participants were trained, baselines were taken, and interventions were conducted separately. The sessions were video recorded, and the videotapes were examined to measure active participation of the subjects and positive affect. Inter-rater reliability and social validity were used to evaluate validity. Data analysis occurred through visual inspection of graphical measures to identify trends, stability of the dependent variables, and changes in level and percent overlapping of data. It appears that, although not stated, a power analysis was performed to analyze changes in behavior from baseline to intervention.

Initially, a MMSE was performed, and then the subjects were instructed and given a bowling game in a Nintendo video game. The subjects had to perform the games 4 days a week for 15 minutes over a period of 3 weeks; then, an evaluation session was performed. The entire study was conducted for a duration of 16 weeks, and it included three follow-up observations 3 weeks apart after the intervention was completed. The research provided strong evidence that indeed cognitive function can be maintained with increased physical activity, increased cognitive stimulation, and increased social engagement (Weybright et al., 2010). There is a positive effect on cognitive function

with mental and physical activities (Weybright et al., 2010). One of the participants, Martha improved—from her baseline, attention to task was 25% and positive affect was 1%. At the end of the study and in follow-up visits, her attention to task was 95%, and positive affect was 16% (Weybright et al., 2010, p. 9). Another participant, Judy's initial scores of attention to task was 94% and positive affect was 3%; at the end and during follow-up visits, her attention to task was 99%, and her positive affect was 12% (Weybright et al., 2010).

The last study of this section was a quantitative Prospective Longitudinal Cognitive Study by Belleville et al. (2014). The study investigated 122 older adults with single-domain or multiple-domain amnesic MCI to identify cognitive tests that are predictive of the progression of MCI. The patients were recruited from memory clinics in Montreal, Canada. Questionnaires and diagnostic tests were used to obtain information. Clinical and experimental tests measured the participants' cognitive functions; then, they were followed over 15 years to measure changes in their cognitive status. The subject with no evidence of cognitive decline or no progression to dementia were said to have stable MCI. The baseline of the study, ANOVA or *t*-tests were used to compare subject with stable MCI and progressive MCI. Logistical analysis was used to predict progression of MCI. Correlation matrix was used to exclude certain variables for this exploratory analysis study. The Kaplan-Meier method was used to measure possibility of crossover information if some patient happened to fall in the score distribution. Finally, log-rank test was used to assess survival curve when needed. SPSS-20 was used to analyze data. The major difference noted was that the ANOVA revealed that the participants with more impaired performance progress to more cognitive

decline than those who did not. However, logistic regression analysis revealed a significant predictive value of 87.8% based a specific model of memory measures used. The recommendation is that both non-memory and memory measures are best used to evaluate future cognitive functions. It is challenging at best to predict the progression of MCI; however, cognitive measures do provide important data on the progression of MCI with a sensitivity value of 85%.

Two of the studies reviewed focused on the care of patients with MCI and the progression of MCI. One study found that it is an extremely difficult task to identify the individual with MCI who will progress to dementia. The same study examined the progression of mental decline and the effects of cognitive training to the progress of dementia verify that mental stimulation had the tendency to slow the process of cognitive decline; however, only two patients were used. All of the articles reviewed demonstrated that MCI affects the overall well-being and safety of the individual, from inactivity to lack of stimulation, despair, and loss of autonomy. All of the articles cited the economic impact of the disease process. The articles reviewed demonstrate that the diagnostic process can be tedious and labor intensive, and the person must go through many diagnostic processes to arrive at a diagnosis. Usually, there is a waiting period to see if the syndrome will be resolved versus the possibility of long-term cognitive impairment. The waiting process is anxiety producing for the patients and their families. This inquiry intended to explore and understand the essence of the lived experience of Haitians with MCI in South Florida. It researched lived experiences that have not been previously addressed in the Haitian population of South Florida.

Mental Health in Haiti

The scholarly studies about Haiti are mostly from nongovernmental organizations (NGOs). These NGOs include international colleges and universities that are conducting research in Haiti. Mental health in Haiti is not systematically addressed due to a lack of infrastructure, misconception on mental health illnesses, stigma associated with mental illness, and financial factors. This literature review addresses such disparities. Four scholarly articles will be discussed below regarding mental health in Haiti. MCI is included under the umbrella of mental health since research studies regarding MCI in Haiti are scarce.

A paradigm shift occurred when Khoury et al. (2012) explained that the factor that is influencing mental health treatment in Haiti is not necessarily the culture of voodoo, but it is a system of both individual and external factors that are influencing choices. The researchers wanted to explore and understand which treatment-seeking pathways an individual would choose based on mental illness that is believed to be supernatural. Using a mixed-method ethnographic approach, Khoury et al. used an explanatory model to examine whether voodoo was an obstacle to psychiatric treatment in rural Haiti. The researchers wanted to understand the factors affecting health-seeking behaviors in Haiti. Thirty-one purposive, semi-structured interviews were conducted with community leaders, traditional healers, religious leaders, and biomedical providers. Ten focus groups and four case studies were conducted in Plateau Central, Haiti. The audiotaped interviews were conducted in Creole and French and were then translated to English. The data were analyzed by using MaxQDA10 and codes in English to find themes. Three major themes were identified. Some of the results were “in press” and

were not reported. This qualitative study overall illustrated that a lack of infrastructure for mental health, knowledge of mental illness, reliability of the services provided, and culture all play a major role into health-seeking behaviors of Haitians. The study identified that a biomedical system was used by some patients and families; nevertheless, these mental health services are frequently not available, and when and if these services exist, there is no follow-up treatment system (Khoury et al., 2012). The study further explicated that indigenous and biomedical approaches to health care can coexist to provide a better solution to the patients affected with mental health illnesses.

Another inquiry featured a case study conducted by Partners in Health (PIH) in Haiti (2012). The purpose of the inquiry was to deploy a mental health care model and to evaluate its usefulness. This occurred after the earthquake of January 2010 where mental health disparity was fully evident. The local agency Zanmi Lasante and PIH provided 20,000 individuals with mental health care. The group recognized that the individuals needed both acute care responses and long-term care for the mental health problems that were encountered. PIH developed a model called the 5 x 5 intervention model to plan clinical services. The model is intended to empower the psychiatrist in multiple ways to promote, prevent, and direct mental health care services. This case study stemmed from the four core mission statements of PIH to provide and build local capacity for the long-term delivery of mental health care services. “Direct service delivery, research, training, and advocacy” are the four categories of action of this model (Raviola et al., 2012, p. 68). It was revealed that the mental health needs of the population were neglected prior to the earthquake. The usefulness of the model was demonstrated when the team encouraged people to mourn the deaths of the deceased after the earthquake and when the team

promptly responded to the scare of cholera by educating the population on prevention techniques.

The team of researchers and NGOs are currently training more health care professionals in mental health care services, establishing long-term care settings for continued care, and encouraging qualitative research to better understand local concept of health and illnesses. The 5 x 5 model is a “stepwise process, structured, qualitative information on beliefs, practices, and local priorities about mental health conditions are used to develop a best practice-based template” (Raviola et al., 2012, p. 72). In this model, global mental health initiatives are used to help to strengthen the Haitian mental health care system. With the governmental support, a community-based mental health service structure was developed with this initiative that would be used to sustain, longer-term organizational commitment to developing decentralized mental health services. The new mental health care slogan since 2011 is “With a clear mind, your body is stronger (Ak tèt klè kò a pi djanm)” (Raviola et al., 2012, p. 75). The main purpose of the initiative is to provide safe, effective, and culturally sound mental health care to the population. The researchers explicated that both quantitative and qualitative research are needed to provide baseline consensus of local concepts of mental health and illnesses.

Cianelli et al. (2013) looked at the impact of mental health training in their qualitative study conducted in Haiti. One hundred and thirteen health care workers in the northern part of Haiti were trained to understand mental health issues in Haiti. The mental health training program was implemented to provide knowledge and skills to the workers so they can respond to mental health care needs of the community. Two focus groups were conducted with 16 of the health care workers to understand the responses of

the health care workers to the training program. Content analysis was used to identify and define major themes. To conduct the data analysis and to facilitate data storage, NVIVO 9 was used. Three final themes were identified: personal impact of the mental health training program, professional impact of the mental health training program, and acceptability of the mental health training program. The study was concluded when saturation of data was reached.

The researchers concluded that mental health training can help health care personnel to respond more effectively to mental health care needs in any situation. They also concluded that a great misconception exists regarding mental health and illnesses in Haiti. The report read that in Haiti “someone with mental health problems may be stigmatized, called ‘crazy, stupid’ or ‘possessed,’ and labeled ‘non-functional’ or ‘worthless’” (Cianelli et al., 2013 p. 529). One of the major barriers to mental health care is lack of trained mental health workers and lack of treatment centers to respond to needs. Cianelli et al. (2013) concluded that these training programs should be made accessible to all health care workers of the Caribbean. The researchers called for inclusion of mental health training in curriculum development for health care workers in Haiti. Furthermore, they identified that despite the cultural beliefs and attitudes on mental health in Haiti, the participants showed willingness to change their worldview. The researchers recommended mental health training for all health care workers so that quick and effective responses to disasters can be provided. Cianelli et al. (2013) emphasized that the acceptability of a mental health program depends on the content covered, the mode of delivery of the content, and the culturally appropriateness of the program. They

emphasized that all mental health training services must be kept updated, rehearsed, and evaluated frequently.

The last inquiry for this section is a quantitative study conducted in Haiti explored the factors that are hindering care seeking behaviors of Haitian from a rural segment of Haiti (Wagenaar, Kohrt, Hagaman, McLean, & Kaiser, 2013). The researchers wanted to determine whether culture, cost, and competency were determining factors of health-seeking behaviors of that segment of Haitians. They wanted to determine optimal approaches for expanding mental health care services for patients with mild to moderate psychiatric distress in rural Haiti. A cross-sectional, zone stratified method was used to survey 408 adults ages 18 and older in Plateau Central, Haiti. The survey was conducted in Creole. Random walk protocol was used to obtain the sample. A multivariable logistical regression model was used to determine the hierarchy of choices. SAS 9.3 was used to analyze the data.

Wagenaar et al. (2013) revealed that three out of four rural Haitians claimed they would seek help for mental distress from community resources (e.g., voodoo priest, herbal remedies, churches) instead of clinical care (i.e., biomedical model). Clinical interventions were not used frequently, perhaps because of a lack of consistency in care and a lack of follow-up practices. Thirty-two percent of the respondents indicated they would seek help from God first for mental distress, 29% would go to a clinic or hospital, 25% would go to a family member or a friend, and 8% would go to a priest or a pastor. “They give the best care” was the number one reason for selecting a particular provider (Wagenaar et al., 2013, p. 368). Comfort with the provider was the second reason, distance of provider to the patient was third, “this is the way it is” (Wagenaar et al., 2013,

p. 368) was fourth, and the fifth reason was cost. It is reported that some Haitians have difficulties talking and releasing information on personal issues regarding mental health mainly because indigenous healing and coping practices are shaped by spirituality and religious systems. Wagenaar et al. (2013) documented that the cultural stigma of mental illness might limit health-seeking behaviors. Cost did not seem to be a factor in health-seeking behaviors as much as trust. The researchers recommended that expanding psychiatric services to this population might augment usage of services.

There is a consensus among all of the research studies: It appears that Haitians seek help where it was most reliable, available, and comfortable to them. In some cases, help was provided by a voodoo priest or priestess; in other cases, the biomedical model was used as the last resort not because Haitians do not believe but due to lack of availability of these services (Khoury et al., 2012; Raviola et al., 2012; Wagenaar et al., 2013). Haiti adapted the mental health model of the United States (Nicolas et al., 2012). Nicolas et al. (2012) predicted the post-traumatic stress related to different issues of the 2010 earthquake might affect many Haitians regardless of their location in the world. These symptoms may continue to emerge and be manifested many years to come, and the health care system needs to be ready and equipped to intervene appropriately. One of the most effective ways of providing interventions is to conduct research studies to better understand the phenomenon (Nicolas et al., 2012). This research study will explore the essence of the lived experiences of the Haitian with MCI living in South Florida. Understanding the essence of what drives or guides a phenomenon will eventually lead to better treatment outcome overall.

Mental Health and the Africans Diaspora in South Florida

Today, there is a great deal of debate on how to address mental health issues in the Black community (Harwood et al., 2000). A literature gap exists regarding mental health in Haiti, and a bigger gap exists regarding mental health of Haitians in the United States. Since data is limited, and in an effort to gain understanding of mental health issues, the literature of other cultures will be reviewed. Haitians migrated to the United States since the 1900s, and the biggest influx occurred in South Florida after the dictator Duvalier proclaimed the presidency for life in 1964 (Colin, 2009). Today, there are 182,224 Haitians in Florida; consequently, Florida holds the largest number of Haitians born in Haiti, and the hub of the Haitian cluster is called Little Haiti in Miami, Florida (City-data.com, 2014). A gap in the literature exists involving Haitians with MCI in South Florida. No articles were found that address mental MCI of Haitians in Florida or the United States. One promising non-profit organization that is providing important and much-needed mental health care services to Haitians in Haiti and in the New York is CapraCare, but the group has not yet published any scholarly research articles regarding their service and/or studies.

Various stigma, typically referred to as memory problems, are associated with mental illnesses in the Chinese, Caribbean, and many other cultural groups or populations (Benbow & Jolley, 2012). In a cross-sectional study on community-dwelling Blacks in Miami, Florida, Harwood et al. (2000) explained that the dementia is usually found at a much significantly later stage in the Blacks and Afro-Caribbean than their Caucasian counterparts (Harwood et al., 2000). The view of dementia as being normal aging and the stigma associated with the diagnosis of dementia worsen the process of diagnosis and

treatment of the syndrome. The purpose of the quantitative inquiry was to investigate the prevalent rate of major depression and psychosis among Black patients in the community and to examine the factors influencing the relationship of mood disturbance and psychotic symptoms of the same population. According to Harwood et al. (2000), “research efforts have failed to reflect cultural diversity of the population” (p. 425). They continued to emphasize that investigation of behavioral and psychological problems is of utmost importance in this population. The ramifications of these illnesses cause caregivers distress, risk institutionalization of the individual, and impact the clinical course of the disease process. Moreover, the economic burden is expected to increase in the next few decades. Fifty-Five English-speaking Blacks of average age 76.4 years old participated in the study.

Blacks were classified as people born in the United States or in the Caribbean with an African ancestry. Volunteers were recruited from the University of Miami and Mount Sinai Medical Center memory and outpatient clinics. Formal testing of the patients was performed to establish diagnosis, and structured clinician interviews were conducted. The MMSE was used to determine global cognition of participants; the mean MMSE score was 12.8. An extensive psychiatric evaluation was conducted on each subject. In addition to the patients affected, the primary caregiver as an informant was also interviewed. Multiple logistic regression analysis factors were associated with major depression or psychosis. Risk factors were explored with a 95% confidence interval. Education was considered as a continuous variable in the analysis; the results revealed that depression was not increased based on the following information about the patient: “age, gender, level of cognition, and comorbid psychosis” ($OR = 1.31$; 95% $CI = 1.06$ to

1.73; Wald $X^2 = 4.9.2$; $p < 0.05$) (Harwood et al., 2000, p. 426). The logistical regression analysis for psychosis revealed no increase in risk of psychosis related to age, gender, education, and comorbid depression (OR = 1.21; 95% CI = 1.07 to 1.40; Wald $X^2 = 7.2$; $p < 0.05$) (Harwood et al., 2000, p. 426).

Twenty percent of the subject had major depression, while 58% had some form of psychosis. Lower education was linked with mood disorders, whereas severe cognitive dysfunction increased the risk of psychosis. Harwood et al. (2000) concluded “it is clear that continued research in the area of ethnicity and dementia is warranted to better understand the clinical needs of Blacks and other minority populations in the United States that are affected with AD” (p. 424). The final recommendation was for continued investigation to understand the clinical needs the population. More outreach programs are needed to facilitate early diagnosis and treatment of the community-dwelling Blacks.

One mixed method study conducted by Douyon et al. (2005) focused on the relationship of traumatic experience and undesirable behaviors among Haitian youths in two zones of Miami/Dade County. The researchers indicated that not only did these youths of Miami encounter daunting barriers as immigrant groups through their journeys to the United States, but in Miami, they were further disenfranchised by a system that ghettoized them. The Haitian group was further marginalized by linkage to disease such that in 1982, the CDC linked them with the AIDS and TB epidemic in the United States. In Miami, conditions of poverty, unemployment, and underemployment are notable. Until today, the community distrusts researchers, especially if they are studying HIV and AIDS. The researchers indicated these youths of Miami were traumatized because of many factors including but not limited to political killings and torture witnessed in their

homeland, death of fellow travelers during boat migration, mistreatment in holding camps and temporary quarters upon their arrivals in the United States, and abuse at the hands of stepparents.

Recruitment was conducted through street-based contacts in network of informal social relations. The investigators interviewed 292 Haitian youths, ages 12-25, who self-reported activities including gangs, drug use, fighting, criminal activities, and prior exposure to violence or stressors. A subset of the group (seven youths) received an assessment using the Clinician Administered Post-Traumatic Stress (CAPS) interviews. SPSS was used to analyze the responses from the interview. Forty-seven out of the 288 youths in the study had Post-Traumatic Stress Disorder (PTSD). The 47 youths had a second interview using the CAPS tool. SPSS was used to analyze the interview questions. Power analysis with one-way ANOVA was used to evaluate variables. The researchers revealed that traumatic experience was not a precursor to the youth joining a gang. They concluded that trauma has an impact on those who experience it; however, the data did not show a correlation between delinquent behaviors and traumatic experiences. Mental health outcomes might be influenced by traumatic experiences, but they do not necessarily lead to PTSD, and they do not appear to be related with behaviors associated with gangs (Chi-square = 1.811, $p = 0.404$; Chi-square = 0.135, $p = 0.713$) (Douyon et al., 2005). The researchers reported that the qualitative inquiry result exhibited normal social skills of the youths. These youths verbalized positive adaption to change after PTSD. There were no psychopathic tendencies detected in the youths as a result of the trauma or PTSD.

In 2008, Lawrence, Samsi, Banerjee, and Murray designed another qualitative study regarding Afro-Caribbeans with Alzheimer's disease. The study was designed to explore the attitudes, needs, and experiences of Black Caribbean, South Asians, and White British carers. Lawrence et al. (2008) reported that among the ethnic minority population in the UK, the family members provide most of the dementia care because the group is not likely to solicit help from the health care system or social services. The researchers wrote that two-thirds of older people with dementia in the UK are supported in the community by family members. They recognized that the understanding of the nature of the disease and the need of the carers might vary between ethnic groups. A grounded theory approach was used to interview 32 carers ages 33 to 87 years old; among them were 10 Blacks, 10 South Asians, and 12 White British carers. Some of the participants were from deprived inner-city groups, as well as participants from wealthy suburbs.

The semi-structured interviews were conducted in the language most comfortable for the participants; the interviews were audiotaped and transcribed verbatim, and the interviews continued until saturation was reached. Data collection and analysis occurred at the same time. The researchers divided and interpreted the data. During data analysis, codes and then themes were identified until consensus was reached. Thereafter, conceptual categories were formed. The results revealed that culture plays an important role on the attitude of the carers; moreover, they revealed that traditional and non-traditional ideology of caregiving influenced the responses to AD. Conceptualized ideology of caregiving was viewed as natural, expected, and virtuous. Cultural attitudes

towards caregiving played an imperative role in caregivers' responses such responses were that of fulfillment, strain, carer's fears, and attitudes toward formal services.

Religious values influenced traditional ideology; therefore, the majority of the South Asians and Black Caribbeans who were religious held traditional ideologies. Carers with traditional ideology were willing to care for their family members with AD, and they often viewed their services as a chance for reciprocity of services, whereas carers of non-traditional ideology viewed caring for the affected person as a burden. They avoided caring for the AD patients, which brought feelings of guilt and duress. The researchers believed that the responses regarding AD were culturally influenced—the carer with African ancestry and the Asians carers were less stressed or burden by the caring experience (Lawrence et al., 2008, p. 242). “There remains a fundamental knowledge regarding how dementia is understood, experienced, and managed among black and minority ethnic groups in the United Kingdom and elsewhere” (Lawrence et al., 2011, p. 40). Public and professional awareness needs to be raised regarding Alzheimer's disease and particularly regarding minorities with Alzheimer's disease or dementia (Hendrie et al., 2001; Lawrence et al., 2008, 2011; Mok, Lai, Wong, & Wan, 2007; Sun et al., 2012).

The purpose of this next inquiry was to determine the cultural and ethnic influences of dementia on caregiving in Chinese Americans families; a systemic review and analysis of already published research was conducted (Sun et al., 2012). The researchers wanted to understand the role of ethnic or cultural values in the process of caregiving; therefore, they reviewed 18 research findings dated between 1990 and 2011 on Chinese American family caregivers. The researchers explained that a sociocultural

stress and coping model that was developed by Aranda and Knight, although the model is not sensitive to Chinese Americans. The model is only sensitive to Latinos and African Americans. They argued that various situations and specific stressors could be triggered differently and dealt with differently across ethnic or cultural groups. Eighteen scholarly English-language studies were identified for analysis. Codes and themes were identified. Ten of the articles were qualitative studies, while the remainder was clinical trials or surveys. Twelve of the studies were from the Boston area, followed by five from San Francisco and one from Los Angeles.

Seven themes were identified: (a) perception of dementia, (b) family harmony and filial piety, (c) seeking diagnosis and treatment, (d) caregiving stressors and psychological distress, (e) coping and informal support, (f) formal service needs, barriers and utilization, and (g) culturally competent interventions.

Perception of dementia – folk models of health was entwined into the Chinese American caregiver’s perception of dementia. Dementia was viewed as “fate, wrongdoing, craziness, a result of worrying too much, or contagious” (Sun et al., 2012, p. 14). Dementia is viewed as a normal aging process or stigmatized as mental illness and could be viewed as a humiliation factor for the family (Sun et al., 2012). Family harmony and filial piety means to honor to one’s parents. A disharmony occurs with the diagnosis of dementia; it is believed the diagnosis prevents reciprocal responsibilities between children and parent, which means if dementia affects the parent, then a failure is occurring in the filial responsibilities of the parent. For the theme seeking diagnosis and treatment, Chinese cultural stigma may cause delay or result in avoidance of care seeking behaviors from biomedical models. Due to respect for professionals called “differential

silence,” the Chinese elder might accept a misdiagnosis of normal aging for dementia symptoms. Caregiving stressors and psychological distress were very palpable. Emotional well-being is affected by cultural beliefs; the diagnosis of dementia might cause undue stress secondary to the potential linkage to the stigma of mental illness. Regarding the theme coping and informal support, the dementia diagnosis could be seen as a shameful event, and the family deals internally with the stressors. They run to religion. Neighbors and other family members might be avoided due to the diagnosis. One major issue that surfaced was the acculturation of sons and daughters to the American culture where they shy away from the responsibility of taking care of their elderly parents in the United States. Formal service needs, barriers and utilization mean that language barriers, lack of mental and medical services, stigma of illness, and mistrust in professional services all play a role in the barriers to the lack of help-seeking behaviors. Finally, regarding the theme of culturally competent interventions, three of the studies developed interventions to assist the elder Chinese at home. The researchers emphasized that “Chinese cultural values are central to these interventions” (Sun et al., 2012, p. 18). Psychotherapy is traditionally not viewed positively. The interventions that were designed to be done at home were more successful than institutional ones. A DVD format of the intervention was prepared to avoid repeated home visits, which was also viewed as a negative stigma. Providing care that demonstrated respect to the culture was very successful (Sun et al., 2012).

Sun et al. (2012) ascertained that because the population is rapidly growing, more research is needed to ameliorate racial/ethnic disparities in terms of prevention and intervention regarding dementia. The researchers recommended rigorous research that

incorporates Chinese cultural and family values so that the population can receive better services. They emphasized that the prevalence of cognitive disease is increasing; thus, the research efforts on the affected population must increase as well. Chinese families incorporate folk models (non-biomedical terms) of the disease process and management in their explanation of dementia. Consequently, the Chinese Families usually perceive dementia as a normal aging process; that belief might hinder the individual's health-seeking behaviors. Nursing professionals must be aware of such cultural nuances in order to better serve the community (Sun et al., 2012).

The majority of the articles identified the need for further research involving this rapidly growing population of elderly patients regardless of their ethnicity. All of the articles concurred that the well-being of the patients and their families and caregivers are adversely affected by the cognitive dysfunction on MCI or dementia. The articles about dementia are used due to a lack of information on MCI and the non-White population. Among all of the articles reviewed, there is a consensus that understanding the lived experiences of people affected with cognitive impairment or dementia will diminish the financial burden on the patients, the family, and the health care system. Additionally, it should help to diminish the anguish associated with cognitive diseases. All of the articles emphasized the cultural stigma associated with mental health issues regardless of ethnicity. Unfortunately, few articles were found regarding MCI. Furthermore, some of the articles grouped all Blacks in one group regardless of the idiosyncrasy that exists among different cultural groups. It is true that because of African ancestry, Blacks carry some of the same traditional beliefs and values, but some racial or ethnic disparities or emic views or values differ among all of the cultural groups. This researcher explored

and understood the perspective of Haitians regarding MCI. Since a research gap exists, the researcher proceeded with the study. It was hoped that based on the research findings that the quality of life of the patients affected with MCI could be improved regardless of the cultural descent of the individual.

Experiential Context

This researcher's prior connection, experience, values, and feelings about the study are expressed in the experiential context section. Subramoney (2013) explained that "the experiential context is valid in any research to ensure that the researchers are vested in their research" (p. 49). Many philosophers argue that the phenomenon of study should be of interest to the researcher. Experiential context is used to reflect the researcher's experience with the concept of the study and is used to allow the researcher to acknowledge and discuss prejudices and biases to permit effective bracketing (Munhall, 2012).

I was born in Haiti, but most of my formal education has been obtained in the United States since my migration to South Florida in 1988. I graduated as a Geriatric Nurse Practitioner in 2007. I became a nurse and have been working with the elderly since she was in high school. At the beginning of that experience, I would volunteer in the nursing homes and then became employed as a nursing assistant. The researcher has always been working with the elderly population, and it is my passion and honor to be able to assist them in any ways that I can. Living in South Florida made this devotion very convenient to obtain employment with a strictly elderly community. Other than my family experiences with the Haitian community, the researcher has not had an extensive contact with elderly Haitian patients with or without MCI in South Florida. Being a

nurse and a Haitian has brought my attention to the needs of the Haitian population. In the Haitian cultural heritage, mental illness is a taboo or a stigma (WHO, 2010). Most elderly clients with MCI are classified as being “simply old” by this culture.

Consequently, impaired cognition is viewed as normal part of aging, and it is viewed as unnecessary to be treated or alleviated.

Reflexivity is an important component of qualitative inquiry since qualitative researchers have a risk of being biased secondary to the vested interest in the research inquiry. I was always aware during the entire study not to present my views instead of reflecting the views and beliefs of the participants. Reflexivity increases the researcher’s accountability to stakeholders by establishing trustworthiness; trustworthiness is established with reflexivity; to achieve such, journaling, memoing, maintaining accurate data, and reviewing emotions and values throughout the study are key (Munhall, 2010). Semi-structured interviews were conducted, interviews were tape recorded, and member check was performed. Throughout the entire process, journaling and memoing were performed regarding the researcher’s experience. Epoche, although not completely achievable, was used by putting aside the researcher’s presuppositions and by keeping an open mind to understand the phenomenon through the participants’ perspective (Munhall, 2012). Data analysis was conducted using textual and structural description to capture the essence of the experience. Mok et al. (2007) noted that, “By identifying appropriate care, families, nurses, and other health care professionals can make a difference in the lives of the people with dementia despite their cognitive deficits” (p. 592).

Understanding the person with MCI syndrome might help to promote well-being of the person and to improve their quality of life. From a Haitian perspective, understanding

MCI might provide a positive impact on the quality of care that the patients receive, and that, in turn, might improve their quality of life.

Chapter Summary

This chapter discussed the historical context of MCI, mental health in Haiti, and mental health issues related to Haitians and the Africa diaspora in South Florida. The experiential context of the researcher was presented. The literature research reveals a gap regarding MCI or mental health issues about Haitians, particularly in South Florida.

From many cultural perspectives of the Chinese, British, and African Americans, there is a clear delineation that cultural beliefs influence responses to the disease process, health-seeking behaviors, and the caregiving experience. Through this literature review, it was demonstrated that continued research is needed for the disenfranchised Haitians with MCI who are living in South Florida. It was also evident that the mental health disparity among this group needed to be further investigated.

CHAPTER THREE

METHODS

The purpose of this qualitative phenomenological study was to explore and understand the essence of the lived experience of Haitians with MCI in South Florida. This information might improve the well-being and safety of Haitians in South Florida. Phenomenology allows the researcher to capture meanings and essences of the lived experience from the participants. With phenomenology, in-depth interviews can be used to obtain information. This methodology is based on the interpretivism paradigm, which means the researcher will make interpretations of what she hears, sees, and understands from the participants. This chapter includes an overview of qualitative research, the phenomenological method used to gather data and for data analysis, and rigor of the inquiry.

Research Design

Research design is a blueprint that guides a study. It is a logical, organized, overall strategy chosen by the researcher to integrate different aspects of a study. The purpose of a research design is to ensure that the researcher effectively addresses the identified problem and the research question. It also ensures that evidence obtained enables the researcher to clearly and unambiguously articulate the answer to the research question initially posed. Consequently, the research question for this study was: What is the lived experience of Haitians with mild cognitive impairment who are living in South Florida? Two types of scientific research designs exist: quantitative and qualitative. Quantitative research is based on the positivist paradigm, which is grounded in theoretical belief; this approach generally involves generation of hypothesis and testing

and relies on experiment and manipulation. The results can be generalized secondary to the large mathematical sample, which can represent population. The purpose of quantitative research is to answer the “what” is happening of research; the epistemological assumptions are that knowledge is objective are deductively generated from a hypothesis (Munhall, 2012; Subramoney, 2012). On the contrary, this researcher was interested in the “why” a certain phenomenon of interest is happening; therefore, the post-positivism paradigm assisted her in answering that question. Phenomenology, which is both a philosophy and a method, is one of the qualitative methods that was used to conduct the study. The framework of a study was provided by the research design.

Qualitative Research

The paradigm or worldview is defined as a systematic set of beliefs that provide a framework for the research inquiry (Lincoln & Guba, 1985). To construct meaning of a phenomenon, the interpretivism paradigm is used. Qualitative research asserts that a research phenomenon cannot be seen objectively from the outside (emic view); the researcher must be present and involves from the inside (epic view) to properly understand the experience of the participants. The goal of qualitative research is to increase the understanding, explain a phenomenon, or discover meaning of a phenomenon (Crotty, 1998). In qualitative research, the findings of the research are not generalized. The researcher is interested in the perception of the individuals vis-a-vis an event or their environment; therefore, the findings are subjective. The epistemological assumptions of qualitative research state that knowledge is gained inductively from personal experience of the individual. To maintain objectivity during qualitative research, a succinct data collection and analysis plan is used, along with bracketing or

epoche (Creswell, 2013). The qualitative researcher has to make sure the study is trustworthy and credible by utilizing rigor.

Phenomenology as a Method

Qualitative research has several approaches, and an approach is usually chosen based on the purpose of the study and the research question. This study used the exploratory research design of phenomenology. Phenomenology assisted the researcher in understanding the phenomenon of interest. It is focused on understanding the essence of the experience. Phenomenology allowed the researcher to gain a deeper understanding and find meaning and interpretation of the lived experience of Haitians with MCI in South Florida. Phenomenology assists the researcher with the reasoning and the measures for the research. Interviews were used as a method to collect information, and data analysis was performed by transcribing and evaluating findings until saturation was reached. Themes were drawn out from the interviews.

Phenomenology was chosen for this study because it is grounded in a social constructivist view. The attempt was to make sense of the phenomenon in the participants' world as they describe it. This interpretive framework grounded in social constructivism articulates that there are multiple realities that are constructed by the person's lived experience and through interactions with others (Creswell, 2013). Phenomenological method is based on the work of Husserl and Heidegger. Max van Manen is one of the contemporary phenomenologists who has expanded on the earlier and middle period. His philosophical perspective was used in this study.

Phenomenology is over 100 years old and was founded by Edmund Husserl (1859-1938), who was a German philosopher. Husserl is considered to be the father of

phenomenology, and he developed phenomenology to establish psychology as a science. Husserl introduced phenomenology during the mid-1890s, and he believed in the “essence” of the experience. Husserl was a student of Franz Brentano (1838-1917) who is credited as the first person to develop the basic approach of phenomenology. He wrote extensively about consciousness; he was concerned about the distinction between the “mental and nonmental,” and described the term “intentionality” or the internal experience of being conscious of something (Munhall, 2012).

Although Brentano first wrote about phenomenology, it was Husserl who advanced phenomenology with his student Martin Heidegger (1889-1976). They explored the “lived world” and focused on “essences.” Martin Heidegger believed that interpreting meanings is influenced by cultures, history, and worldviews. He introduced the concept of “Dasein” or “being there.” The phenomenology of Heidegger was further enhanced by the works of Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961) (Munhall, 2010). Phenomenology continued to advance during the 20th century thanks to the works of Van Kaam, Giorgi, Parse, and van Manen (Creswell, 2007). Phenomenology is used in many fields such as nursing, social sciences, health sciences, psychology, and education to better understand their sciences. Phenomenology draws ideas from philosophy, psychology, and education (Creswell 2013).

Hermeneutic phenomenology is concerned with research about the lived experience of a group of individuals and the interpretation of it. It is used to uncover the meaning of everyday life. Max van Manen combined hermeneutic and phenomenology and developed six activities to understand the lived experience of people. Van Manen’s six research activities for reflecting and interpreting the phenomenon are: (a) turning to

the nature of lived experience, (b) investigating experience as we live it, (c) reflecting on essential themes, (d) describing the phenomenon through the art of writing and re-writing, (e) maintaining a strong and oriented relation to lived experience, and (f) balancing the research context by considering parts and whole (Subramoney, 2013). These six activities can occur simultaneously. Figure 3 illustrates these six research activities. The lived experience of Haitians with MCI in South Florida serves as the center and is surrounded by the six phenomenological activities. The activities are connected, but any activity may occur at any time. There is no hierarchy of orders in the six activities.

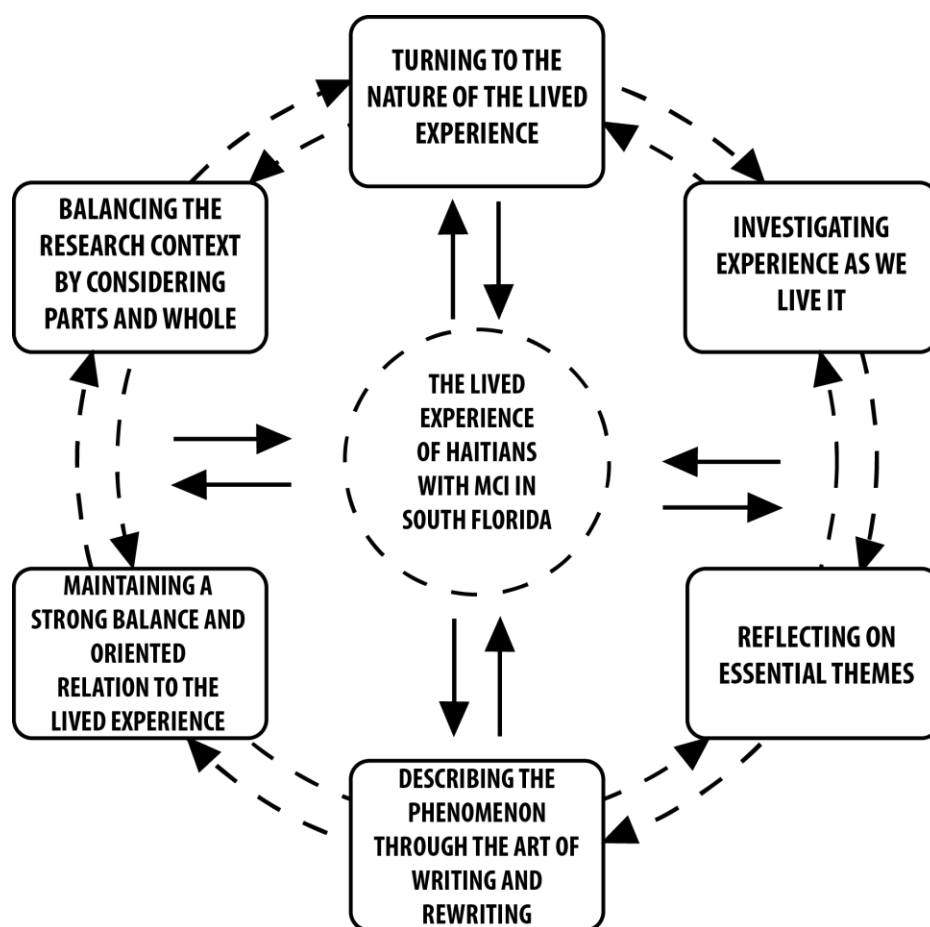


Figure 3. Six research activities.

The central phenomenon of this study was how Haitians experience mild cognitive impairment in South Florida. Turning to the nature of lived experience, by being Haitian and a geriatric nurse practitioner, this researcher was interested in the lived experiences of Haitians with MCI in South Florida. Investigating experience as we live it involved obtaining a deeper understanding and meaning of the lived experience of Haitians with MCI; this researcher explored the scope of the lived experience. Epoche is used to limit biases while the researcher remains open to the interpretation of the lived experience. To reflect on essential themes that characterize the phenomenon, the diverse genre of art was used to obtain meaning into the lived experiences because art, photos, music, poetry, and literature are intertwined in the Haitian daily lives (Colin, 2009). Vicariously, the researcher used a contextual approach to explore and describe the meaning of the experiences of Haitians in South Florida.

To describe the phenomenon through the art of writing and re-writing, with the guidance of the dissertation committee, the researcher reflected and described the data obtained. Two approaches were used to examine the data collected. The line-by-line and the highlighted approaches assisted the researcher to linguistically transform the data to capture the essence of the themes. Data were written and rewritten numerous times for the meaning of the experiences to emerge. Through journaling and field notes, both body language and speaking language were captured. The final report of the inquiry conveyed the meaning of the experience of Haitians with MCI in such a way that readers can understand it. To maintain a strong and oriented pedagogical relation to the lived experience, Haitians were asked to describe what it is like for them to experience memory problems or MCI through a narrative dialogue. The data in concordance with

the lifeworlds was reported with narrative descriptions. Balancing the research context by considering parts and whole: The research was grounded in a phenomenological perspective so that the Haitians could freely express their lived experiences. The researcher maintained the rigor of the inquiry through reflexivity. The whole lived experience of the individuals was explored and described through descriptive and interpretive text (Munhall, 1994; van Manen, 1990).

Sampling and Setting

The sample selection for this study was purposive, consisting of 21 Haitians who have experienced MCI. Purposive sampling allowed for the collection of a rich description of what was happening in the life of the participants in order to provide an understanding of their experience (Berg, 2012). Snowball sampling occurs when one participant refers the next participant to the study. Snowball sampling was used although it could have been difficult to recruit participants through snowball sampling in this study since mental health is stigmatized in the Haitian culture. As previously explained, in the Haitian culture, mental health issues are usually not discussed in casual conversation. The researcher selected a small group of individuals who have experienced MCI and who met the inclusion criteria to participate in the study. Although each participant experienced the phenomenon of interest differently, according to Creswell (2013), all of the participants needed to share the same phenomenon of interest in order to have been included in the study. Researchers use well-defined characteristics and demographic information to locate the sampling group (Creswell, 2013). The participants were selected from churches, health clinics, and any formal or informal gathering places in the communities of South Florida. A maximum of 25 participants were selected for the study

because Creswell (2013) suggested for an effective qualitative research study, 20-30 participants will suffice to get a rich description of the phenomenon of interest.

Potential participants included persons who self-report memory problems. The potential participant should have already been diagnosed with mild cognitive impairment (MCI). Potential participants could have had a preexisting history of MCI. If available, an MMSE score could have been provided. If an MMSE score was not available, this researcher did not test the participants. Prior cognitive testing was not a prerequisite for admittance to the study. The etiology of the MCI was not relevant for this study. Participants must have been 55 years old or older. They had to be of Haitian heritage and be able to speak Creole or English. They did not need to know how to read. Flyers in Creole and English containing information on the description of the study, the purpose of the study, and who can qualify to participate in the study were posted. The flyers (see Appendix D) were placed in the common community areas. Interested participants called the researcher for more information. One means of recruitment was that the researcher had set up one opportunity session at a well-known busy local primary health care provider's clinic to recruit perspective participants and to provide information about the study. In addition, the researcher visited well-known health clinics in South Florida with a large Haitian population to obtain permission to recruit participants. An initial telephone interview or an information session was conducted to determine eligibility of participants, the inclusion and exclusion criteria were determined, and then face-to-face interviews were conducted.

Access and Recruitment of the Sample

Upon approval from Barry University Institutional Review Board (IRB), the researcher contacted churches, health clinics, private physician's offices, and community centers that services the Haitian community of South Florida via email and in person (see Appendix C) to request permission to post flyers at their sites in order to recruit participants for the study. Pillars were contacted for guidance and entry into the community. The researcher reassured the responsible parties at the setting locations that the study was independent of any hidden agenda or biases and that there were no risks in participating in the study. Once approved by the IRB and agreed upon by the representatives of the various recruitment sites, the researcher posted flyers (see Appendix D) in areas accessible to prospective study participants so that they could determine their level of interest in and their eligibility for participating in the study. Additionally, the researcher conducted an information session at one of the sites as another approach for recruitment. Finally, the researcher also recruited a few participants through her personal contacts and snowball sampling methods.

The recruitment flyers identified the researcher as a doctoral student at Barry University, Miami Shores, Florida. It included information about the study, the time commitment required of the participants, the contact information for the researcher, for the IRB representative, and for the research supervisor. The flyer also indicated that all participants in the study would receive a \$25 Walmart gift card. The participants were informed that they would and did receive the gift card whether or not they completed the interview. All of the participants completed the study. The researcher responded to all of

the inquiries from potential participants regarding the study and selected and interviewed those participants who met the inclusion criteria for participating in the study.

Inclusion Criteria

The inclusion criteria required the participants to be Haitians and living in South Florida. The participants were required to be age 55 or older. The participants must have or have had MCI during the study or in the past. The MCI diagnosis could have been a formal diagnosis from a health care provider, or memory problems could have been self-reported by the participant. Participants must have been willing to complete the demographic questionnaire. Voluntary consent was obtained prior to the start of study in either in Creole or English. If the participant could not read or write, consent was verbally obtained on the audiotape with an X on the consent form. The participants may have spoken English or Creole, and they did not need to know how to read or write to participate.

Exclusion Criteria

Haitians who were younger than 55 years of age and or who had not experienced MCI were excluded from the study. Individuals without Haitian heritage were excluded. Participants who did not reside in South Florida, family members or caregivers of the affected participants, individuals with active Alzheimer's disease, and individuals with obvious psychosis were excluded. Additionally, individuals with agitation, suicidal ideations, or with physical aggression were excluded. Interestingly, all of the participants who contacted the researcher were eligible to participate. Finally, individuals who were currently acutely ill with any other illnesses were excluded from the study.

Ethical Considerations/Protection of Human Subjects

This study explored the lived experience of Haitians with MCI living in South Florida using phenomenology as a contextual framework. Qualitative research is considered harmless to the participants, but in reality, some risk, although minimal, could be assessed in certain inquiries. Qualitative research involves the researcher as an instrument of the study. The ethical considerations of this study focused on issues involving potential harm to the participants, the consent process, privacy issues, and confidentiality of the data (Berg, 2012). In this study, no risks of injury were assessed to the participants.

Institutional Review Board approval was obtained from Barry University prior to the start of the study. The guidelines of the IRB of Barry University were rigorously followed to protect all of the participants and to maintain ethical standards. The aim of the study, the proposed research process, and opportunity to ask questions were provided for all potential participants prior the initial interviews. Written informed consent was obtained from all participants before the interview began. If the participant could not read or write, consent was verbally obtained on the audiotape with an X on the consent form. During the initial part of the interview, the participants were informed that they had the right to withdraw from the study without repercussions since the study was strictly voluntary with no risk. They were also advised that there were no direct benefits from the study except that the knowledge obtained will benefit nursing as a discipline. The interviews were conducted in the private setting where the participants could freely express their views and beliefs. The information was kept confidential by using pseudonyms chosen by the participants; this step ensured confidentiality (Berg, 2012).

The data collected were stored in a password-protected computer at the researcher's home. The audio-taped interviews were destroyed after transcription and member check. To show appreciation for their participation in the study, a \$25 Walmart gift card was given to the participants after they agreed to participate in the study and they met inclusion criteria.

Data Collection Procedures

Following Barry University IRB approval, recruitment and data collection commenced. The flyers were sent to the site representatives for posting or distribution. Individuals who chose to participate contacted the investigator based on the contact information provided in the recruitment flyer or they indicated their willingness to participate at the information sessions. Participants who met criteria were interviewed by the investigator using face-to-face interviews at a mutually agreed upon time and setting by the participant and researcher. The face-to-face meetings were held in safe locations. The meeting opened with a welcome and thank you to the participants. If they chose to participate in the study and met inclusion criteria, a \$25 Walmart gift card was given. The participants were informed that the gift card was theirs to keep whether or not they completed the interview. Next, the study's protocol, recordings, and informed consents were discussed with the participants, questions were answered, and clarification of the purpose of the study was reviewed. The participants were informed that they have the right to withdraw from the study without repercussions. If the participant agreed to proceed, then before the interview, the informed consent was signed (see Appendix B). All signed consents were stored by the investigator in a secure cabinet the researcher's home. Next, the participants were asked to self-identify with a pseudonym or have one

assigned by the principal investigator. The demographic questionnaire (see Appendix E) was completed and labeled with the selected identifier and subsequently scanned into the secure personal computer of the researcher.

Haitians are generally private and have difficulty discussing their personal experiences; as such, the interview was started with a vignette (see Appendix F) depicting an individual (Lorencia) who has experienced MCI. Participants were offered a choice of having the vignette read to them in English or Creole. This step is important since a number of Haitians who may have met the inclusion criteria may not have been able to read or write in any language. The vignette was used as a way of stimulating and facilitating the discussion.

The individual interview process was as follows: Participants were given the \$25 Walmart gift card. They were informed that it was theirs to keep whether or not they withdrew from the study. They were next asked to select a pseudonym, which was followed by obtaining the consent. Semi-structured audiotaped interviews were conducted using the vignette and open-ended questions (see Appendix G). Follow-up and probing questions were used to gather the data from the participants to describe meaning and essence of their lived experience with MCI. The participants were informed that there were two scheduled interviews: the first lasting approximately 60 minutes and the second lasting approximately 30 minutes for a total of 90 minutes. These semi-structured individual interviews were recorded using a digital recording device. The audio recorder and the backup recorder were visibly located. The participants verbalized understanding that they could have decline to answer any questions without repercussions.

Upon conclusion of the interviews, the participants were thanked and informed that once the data was transcribed by the researcher they would be contacted to set a follow up interview. Of those who agreed to participate in the second interviews, the interviews took place within a week following the first interview. The purpose of this second interview was for clarification and confirmation of the transcribed data; this step is known as member check. Credibility of findings is a significant step that allows the participant to consider if the transcription indeed reflects their intended statements. Interview protocol is outlined in Appendix H. The hour-long semi-structured interviews conducted in Creole or English, based on individual participant's preference, were audio taped, transcribed verbatim, and analyzed by the researcher. The Creole interviews were translated to English before data analysis. This process was continued until all of the interviews were completed. All data, demographics, recordings, and transcriptions were labeled with the self-identified pseudonym.

The data collected were systematically organized based on the pseudonyms selected by the participants. The researcher analyzed the themes that have emerged from the interviews. The data collected and the field notes were kept separate from the consent forms in a locked file cabinet in the researcher's home. The computer files with transcribed notes were password protected and were kept separate from the signed consent forms. The data will be kept for 5 years after which time they will be destroyed. Data collection is intensely time consuming; qualitative research involves direct observation of the participants, which is time consuming and has a voluminous amount of data to be processed. Thus, only a small sample is needed to obtain rich data. Semi-structured interview questions allow the participants to communicate in an open-ended,

liberated interaction with the researcher, which allowed the participant to freely discuss MCI at a greater depth. The data collection phase involved information from participants such poems, music, documents, and observations (Creswell, 2013). The information provided by the participants and researcher allowed for a richer understand of the lived experience.

Interview Questions

Face-to-face interviews were conducted. A semi-structured interview questionnaire (see Appendix G) was prepared to encourage the participant to communicate about MCI. The foremost interview question was “What do you think about Lorencia’s story?” The second question was “What is it like for you to experience MCI?” These questions were followed by probing questions to clarify and obtain more in-depth responses; probing involves the interviewer asking, clarifying, or elaborating questions about a subject that the interviewee mentioned. Probing involves trying to get more complete answers from the subject (Berg, 2012).

Demographic Data

A demographic questionnaire (see Appendix E) designed by the researcher included basic identifying information from the participants. The data from this questionnaire was used to describe the study population. The reporting of this information was done in aggregate form and through the use of pseudonyms. The demographic information (see Appendix E) needed from the participants included sex, age, marital status, occupation, education, years in United States, religion, diagnostic test if available, and participant’s history of hospitalization, if any. Ethnicity was already established since only the Haitian population was allowed in the study. Religious

affiliation was obtained because “the Haitian way of life is deeply marked by a spiritual superstition” (Louis & Hay, 1999, p. 9). The questionnaire was held securely with the data gathered in a locked file in the researcher’s home office.

Data Analysis

Qualitative data needs to be reduced and transformed in order for it to be understandable and to determine themes and patterns emerging from the study (Berg, 2012; Creswell, 2013). Data analysis strategies are used to analyze the data, intellectualize emerging themes, and make textual and structural descriptions; eventually, the essential experience is explained (Creswell, 2013). The data analysis phase is systematic; it moves from narrow units (i.e., significant units) to broad analysis (i.e., meaning units) (Creswell, 2013). The researcher listens and interprets what is said to meaning units to represent the participants’ collective ideas or themes. The final and ultimate goal of phenomenology is to describe the essence of the experience (Creswell, 2013).

Semi-structured interviews were used as a method to collect information, and data analysis was performed by transcribing the data and evaluating findings until saturation was reached. When saturation was reached, a minimum of two more interviews is recommended to confirm in-fact saturation has occurred (Creswell, 2013). The themes were drawn out from the transcribed interviews. Epoche is used to set the researcher’s preconceived ideas apart so that the researcher can analyze the data from a fresh perspective (Creswell, 2013). Since an audiotape cannot record behaviors, field notes were used to record the facial expressions, body language, other nonverbal behaviors of the participants, as well as the environment, the seating arrangements, the room, location,

and surroundings. Memoing assessed the researcher's feelings and perceptions before and after each interview.

The researcher focused, simplified, and transformed the massive data to a more manageable form. It is vital for the information to be transcribed immediately after the interview since it is in the analysis that themes are determined and saturation is determined. Tables will be used to display the data collected and to assist with transferability of data. The final conclusion of the themes was drawn from the data collection analysis. The results are written and shared with colleagues and the public.

The six major data analysis steps according to Creswell (2013) are as follows:

1. Describe personal experiences through epoche; describe the essence of the phenomenon. Create and organize files for data.
2. Develop list of significant statement. This is called the horizontalization of the data. The researcher groups overlapping statements and non-repetitive statements with equal worth. This is the description of the data.
3. Classify the data into codes and themes by developing significant statements and grouping the statements into meaning units or themes. Memoing is done, which means reading through text, making margin notes from initial codes, and describing the data into codes and themes
4. Interpret the data by developing a textural description of "what happened." The researcher must include verbatim examples.
5. Write a structural description of "how" the phenomenon was experienced. The researcher reflects on the setting and the context of the experience.

6. Describe the “essence,” and provide both textual and visual description of the phenomenon. Represent and visualize the data by presenting narration of the “essence” of the experience in tables, figures, or discussion.

(Creswell, 2013, p. 194)

Max van Manen (1990) developed a hermeneutic phenomenological approach, which includes both a descriptive and interpretive approaches of phenomenology. This methodology merges hermeneutic and phenomenology to uncover the meaning of a phenomenon. Interpretive hermeneutic phenomenology provides deep and descriptive data, and it also gives meaning to the lived experience (van Manen, 1990). In 1990, van Manen developed the hermeneutic phenomenology using six research activities for reflecting and interpreting the phenomenon:

1. Turning to the nature of lived experience
2. Investigating experience as we live it
3. Reflecting on essential themes which characterizes the phenomenon
4. Describing the phenomenon through the art of writing and re-writing
5. Maintaining a strong and oriented pedagogical relation to lived experience
6. Balancing the research context by considering parts and whole (Munhall, 1994; Subramoney 2013)

According to van Manen (1990), the process of reflective analysis is a process of insightful discovery; this analytical process guided this study. The goal of the inquiry was to explore and understand the essence of the lived experience of Haitians with MCI in South Florida. The data analysis process consists of reading and rereading, writing and rewriting so that the researcher can identify and describe the experience of the

participants because hermeneutic phenomenology goes beyond the regular task of counting and categorizing themes. Qualitative data needs to be reduced and transformed in order for it to be understandable and to determine themes and patterns that emerge from the study (Berg, 2012; Creswell, 2013).

According to van Manen (1990), during the analysis process, the meaning of the themes is outlined, which serves as the basis for understanding the lifeworlds. Van Manen does not believe in a step-by-step formula to analyze data in qualitative research. Instead, he developed the six research activities that could be used simultaneously in the research process. The selective highlighting approach was used to interpret the narrative transcripts as suggested by van Manen. The researcher reread the transcript and highlighting the phrases or meaning units using colored markers. The highlighted concepts were used for the composition of textual description of the lived experience of the Haitians with MCI. Universal themes were identified; these themes were used to describe the study. Tables are used to display the data collected and to assist with the transferability of the data. After the conclusion is finalized, the results are written and shared with colleagues and the general public.

Research Rigor

To maintain the value of the research study, rigor must be addressed logically and systematically. Trustworthiness, which is the same as validity in a quantitative inquiry was safe-guarded by using rigor (Lincoln & Guba, 1985). Trustworthiness is achieved when the results of the study resemble the information collected as accurately as possible. Qualitative researchers can be easily biased. The researchers must maintain trustworthiness by making sure aspect like triangulation, peer debriefing, member check,

audit trail, and reflexivity are present in qualitative studies (Creswell, 2013; Crotty, 1998). Bracketing and epoche augment the case for trustworthiness (Creswell, 2013). In bracketing, the researcher sets aside his or her experiences to allow a new perspective to flourish regarding the phenomenon of study.

Confidentiality must be maintained throughout the study. Procedures to protect the confidentiality of participants were implemented. Participants were given the opportunity to self-identify. Confidentiality was assured through the use of self-identifying pseudonyms, records including audio recordings, transcriptions, scanned documents, and a demographic questionnaire containing pseudonyms to identify the participants. The consents were kept separate from the interview data to ensure confidentiality. The consents were stored in a locked file separate from the other study documents. Confidentiality was maintained, as transcriptions, recordings, scanned documents, email, and direct mail data were stored on the password-protected personal computer in the home office of this researcher.

Recorded data were kept until the study was transcribed and printed at which time the digital recordings were erased. Transcription data are kept for a minimum of 5 years on the secure personal computer of this researcher. Findings of the study were disseminated in the aggregate. The researcher acted as a gatekeeper to ensure that identifiable information obtained was not disclosed during the entire research process and that it is to be destroyed after 5 years of safe recordkeeping. The researcher safeguarded trustworthiness in the study by ensuring that credibility, dependability, confirmability, and transferability exist and are properly documented throughout the study (Munhall,

2012). The four criteria of trustworthiness are discussed in the following statements below.

Credibility

Credibility means the information that is obtained is believable and that it represents the accurate words and concepts of the participants. Credibility means the truth, the values, and the beliefs of the participants are voiced or that they were observed and that they are correctly reflected (Lincoln & Guba, 1985). Credibility is established by doing member check, peer reviews, and reflexivity. The credibility of the data was maintained by audiotaping the interviews and verbatim translation of the conversation. Member check confirmed findings. Field notes and memoing also assisted with credibility of the study. Credibility was used as a form of validation of the data (Creswell, 2013).

Dependability

Dependability means consistency. According to Lincoln and Guba (1985), dependability is achieved if another researcher can arrive at the same conclusion using the same data information. Dependability is achieved establishing a narrative of the research process. Audit trails were used to accomplish transparency of the data and of the research process to arrive at the findings. The field notes are kept in a locked and secure location for 5 years. The demographic information is kept separately to ensure confidentiality. The rationale for the philosophical and methodological choices was clearly outlined in an effort to establish pellucidity; thereby, the dependability of the research findings was achieved.

Confirmability

Confirmability means neutrality, which is achieved by repeating or reaffirming evidence from participants. The researcher transcribed verbatim the interviews and confirmed the findings with the participant; this process is called member check. To confirm the results of the study, the manuscript, the interpretations, and the recommendations of the study can be used to trace back to the participants if needed (Lincoln & Guba, 1985). Journaling and personal note-taking was done after each interview so that the research could describe her perception of the meeting.

Transferability

Transferability means reproducible. It establishes that if given the same demographic information, the geographic boundaries, the setting, and the events of the study, then the study could reasonably be reproduced elsewhere and in a different population. When the researcher properly outlines the research process for future researchers, this demonstrates transferability of the study; hence, the study can be repeated in another location with any different population (Lincoln & Guba, 1985).

Chapter Summary

The research design, method, sample and setting, access and recruitment of the sample, inclusion and exclusion criteria, demographic data, data collection procedures, interview questions, and data analysis procedures were discussed in this chapter. Hermeneutic phenomenology as explained by van Manen's approach was used to explore and understand the essence and meaning of the lived experiences of the Haitians with MCI in South Florida. Ethical consideration and protection of human subjects including

epoche were addressed. Trustworthiness concerning the entire research process was discussed. Rigor as it relates to qualitative research was also highlighted in this chapter.

CHAPTER FOUR

FINDINGS OF THE INQUIRY

This chapter highlights the findings of the phenomenological inquiry into the lived experiences of Haitians with mild cognitive impairment (MCI) in South Florida. The purpose of this qualitative phenomenological inquiry was to explore the meaning, structure, and essence of the lived experience of Haitians living with MCI in South Florida. A demographic description is presented in addition to the individual descriptions of the 21 research participants. This study allowed these 21 older Haitians with MCI to share their lifeworlds, thoughts, and feelings, thus depicting the essence of the phenomenon. The stories of the participants described the meaning of their lived experiences. Additionally, the process of data analysis and the thematic representation reflecting the lived experience of these Haitians with MCI will be provided. Finally, the summary of the key findings will be described.

The goal of this study was to explore the lived experiences of Haitians with mild cognitive impairment in South Florida. The phenomenological researcher remained open to seeking the deeper nature of lived experience (van Manen, 1990). Through the participants' personal thoughts and feelings, the researcher was able to describe, interpret, and illuminate the meaning of the Haitian participants in this inquiry. Data collection and analysis of this study was guided by van Manen's six research activities. A brief description of each of the participant is included since it is advised by experts (Munhall, 2007); however, the aim of phenomenological inquiry is to uncover the meaning of the experience (van Manen, 1997). The aim of the inquiry was "to construct an animating, evocative description of human actions, behaviors, intentions, and experiences as we

meet them in the lifeworld” (van Manen, 1997, p. 19). Phenomenological research allows the researcher to bring out the essence, which is usually obscured as compared to what is seen every day. This is achieved by allowing the individuals to express their views freely (van Manen, 1997).

In hermeneutic phenomenology, there is no absolute method; however, van Manen has provided guidance through his six activities, which were used to guide the study. The emphasis is on the data analysis process to capture the essence of the lived experience by reflecting on the themes identified from the interviews. According to van Manen (1990), it is impossible to learn about a lived experience through any secondhand account (e.g., books, journals, discussions); therefore, the phenomenon must be investigated through qualitative phenomenological inquiry, which provides information from the primary source. Consequently, semi-structured, in-depth interviews were used since they supported the study and the phenomenological approach. The semi-structured interview questions were tailored to ease conversation regarding MCI. A vignette was used as a way of stimulating and facilitating the discussion. The individual interview process included obtaining the informed consent, the formation of pseudonyms, the collection of demographic information, and the reading of the vignette. Semi-structured audiotaped interviews were conducted using the vignette and open-ended questions. Additionally, phenomenology allowed the researcher to probe new or potential lines of inquiry based on the responses disclosed by the participants.

Sample Description

Purposive sampling was used to obtain participants for this inquiry. It was uplifting to see a few participants were referred through snowball sampling, which was

not expected but was welcomed. Access was granted through a large and busy Haitian-owned and operated medical clinic with a considerable number of older Haitian patients. On any given day, there were at least 100 patients in and out of the clinic. Responses to the flyers were almost overwhelming. The purposive sampling allowed the researcher to collect information that is deeply enriched. The participants were selected based on the inclusion criteria: being Haitian, being 55 years old or older, and having MCI or previously experiencing MCI. These participants could not have been acutely ill, and they had to have lived in South Florida. The participants did not need to speak or write English, French, or Creole. However, the participants must have volunteered to express their lived experiences with the researcher. Participants must have signed consent as defined by the inclusion criteria.

A total of 21 participants were interviewed. Numerous more patients from the clinic verbalized willingness to participate to the point where they called the primary care clinic to inquire about “the nurse with the memory problem.” This part was saddening and joyous at the same time. Saddening that the community responded to the call so eagerly that they wanted to be studied and joyous because it was rewarding interviewing people who were saying “thank you” for the interview. The conclusion related to the essence of the lived experience of the 21 participants has been shared with detailed narratives to support the findings. A summary description of the individual participants ($N = 21$) is provided later in this chapter.

Demographic Data

The sample size consisted of 21 older Haitian men and women currently with MCI or with the history of MCI who live in South Florida. Saturation was reached when

the ideas and language became recurring and repetitive during data collection. Despite saturation at 15 participants, the remaining 6 participants requested to participate in the study to verbalize their opinions on MCI. One hundred percent of the participants were born in Haiti and immigrated to the United States. Purposive sampling was used, as all participants all met the inclusion criteria for participation in the inquiry. Six of the participants lived in Broward County from Fort Lauderdale to Deerfield Beach; fifteen participants lived in Palm Beach County from Boca Raton to West Palm Beach. The purposive sampling allowed for a rich and diverse group of participants with varied experiences from all walks of life. One hundred percent of the interviews were conducted in Creole per the participants' requests. Demographic data of the participants are listed in Tables 2 and 3.

Although timid, most of the participants were at ease during the interview, so much so that some took off their shoes and some used Haitians idioms that are not typically used with strangers. The narrative descriptions were rich. Haitians typically use figurative speaking during storytelling, using their voice and body language to describe things heard, seen, touched or spoken. The descriptions were very vivid; for example, if the person wanted to express how big something was they would stand up and go on their tippy toes. To describe something loud, they would imitate the sound with their voice, or mouth, or hand. If the sound was loud, then a loud similar noise would be produced and vice versa if the sound was soft. Certain expressions had no words except a description such that the person would place a finger by their mouth to show surprise. Speed would be shown with the flapping of one hand.

Table 2

Participants' Personal Demographic Data

Demographic Survey	<i>N</i> = 21
Gender	
Female	12
Male	9
Age range in years	
55-60	2
61-70	10
71-79	6
80-89	3
90-100	0
Marital Status	
Single	3
Married	14
Widowed	3
Divorced	1
Religion	
Catholic	12
Jehovah's Witness	1
Baptist	8

Table 2 provides information on the participants' gender, age range, marital status, and religion. Among the 21 participants, 12 (57%) were female, and nine (42%) were male. Two (10%) participants were between the ages of 55-60 years old while 10 (47%) participants were between ages 61-70; this age range was the largest group followed by six (29%) participants in the 71-79 age group. There were three (14%) participants in the 80-89 age range, while there was no participant in the 90-100 age range. Three (14%) of the participants were single, 14 (67%) were married, three (14%) were widowed, and one (5%) was divorced. Religion was reported as Catholic from 12

(57%) of the participants, eight (38%) reported being Baptist, and one participant (5%) reported being a Jehovah's Witness.

Figure 4 illustrates the length of time the participants have been living in the United States. Five percent (one) of the participants have been in the United States (U.S.) for 41-45 years. Thirty-three percent (seven) of the participants have been in the in the USA for 31-40 years. Twenty-eight percent (six) have been in the U.S. for 21-30 years; 19% (four) have been living in the U.S. for 16-20 years, while 5% (one) has been living in the U.S. for 6-15 years, 5% for 1-5 years, and 5% for 6 months.

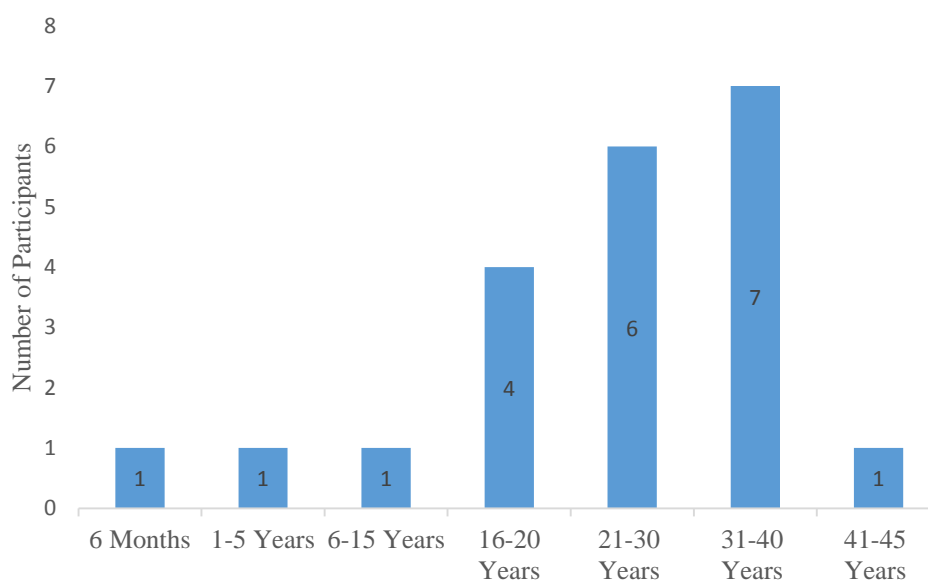


Figure 4. Participants' length of time living in the United States.

Table 3 illustrates the occupation, employment status, and educational levels of the participants. The jobs or occupation ranges from landscaping with 14% (three) participants to the following categories representing 10% (two) each: nursing assistant, dishwasher/food service, truck/bus driver, accounting/musician, gardening, housekeeping, sewing, and merchant/vendor. One (5%) participant was in road

construction, and the last participant (5%) was a housewife. Although the participants described their work as current, 13 (62%) of them reported they are retired. Only three (14%) participants worked full time. No one agreed on being a part-time worker. Five (24%) of the participants described themselves as unemployed, while four (19%) of them were actively seeking employment, and one (5%) participant described himself as permanently disabled. Five (24%) of the participants were never formally schooled; one of the five participants also indicated she attended the alphabetization effort in Haiti as an adult but explained that she was not successful. Seven (33%) participants attended elementary school, two (10%) completed middle school, one (5%) finished high school, and one (5%) had some college outside of Haiti. Five (24%) participants attended some form of technical school.

Table 3

Participants' Professional Demographic Data

Demographic Survey	<i>N</i> = 21
Occupation	
Nursing assistant	2
Service: dishwasher/food	2
Service: truck/bus driver	2
Accounting/music	2
Landscaping/artist	3
Gardening	2
Housewife	1
Service: housekeeping	2
Sewing	2
Construction	1
Vendor/merchant	2

(Table 3 continues)

Table 3 continued

Demographic Survey	<i>N = 21</i>
Employment status	
Full time	3
Part time	0
Retired	13
Unemployed	5
Educational level completed	
No schooling	5
Elementary	7
Middle school	2
High school	1
Some college	1
College	0
Graduate school	0
Technical school	5

As shown in Figure 5, the responses to “Were you diagnosed with MCI?” were daunting. Nineteen (90%) of the participants answered “no” they have not been diagnosed with MCI. Two (10%) participants admitted to being formally tested for MCI. The medical records of all of the participants were not reviewed; dishearteningly, not even one participant remembers his or her MMSE score even though some of them described the MMSE during the interview. When asked, “Were you hospitalized?” seven (33%) participants responded “yes” they were hospitalized in the past few years due to surgical interventions not related to MCI. Interestingly, 39% of the participants currently had some form of cardiovascular disease such as hypertension or angina. Twenty-three percent had diabetes mellitus; 19% had some type of a lipid disorder; 12% had breast cancer, prostate cancer, head trauma due to motor vehicle accident, or osteoarthritis that is causing functional limitations; and finally, 7% had cerebral vascular disease. For classification purposes, the primary medical diagnoses were coded first to

capture a percentage of illness among the participants; however, many of the participants had more than one comorbid condition or precipitating event. This information is significant since according to the NIH (2016), certain health conditions can affect the health of the brain — “for example, heart disease and hypertension can lead to stroke and related dementia” (May 17th 2016 NIH [http: 1usa.gov/1qodNRT](http://1usa.gov/1qodNRT)).

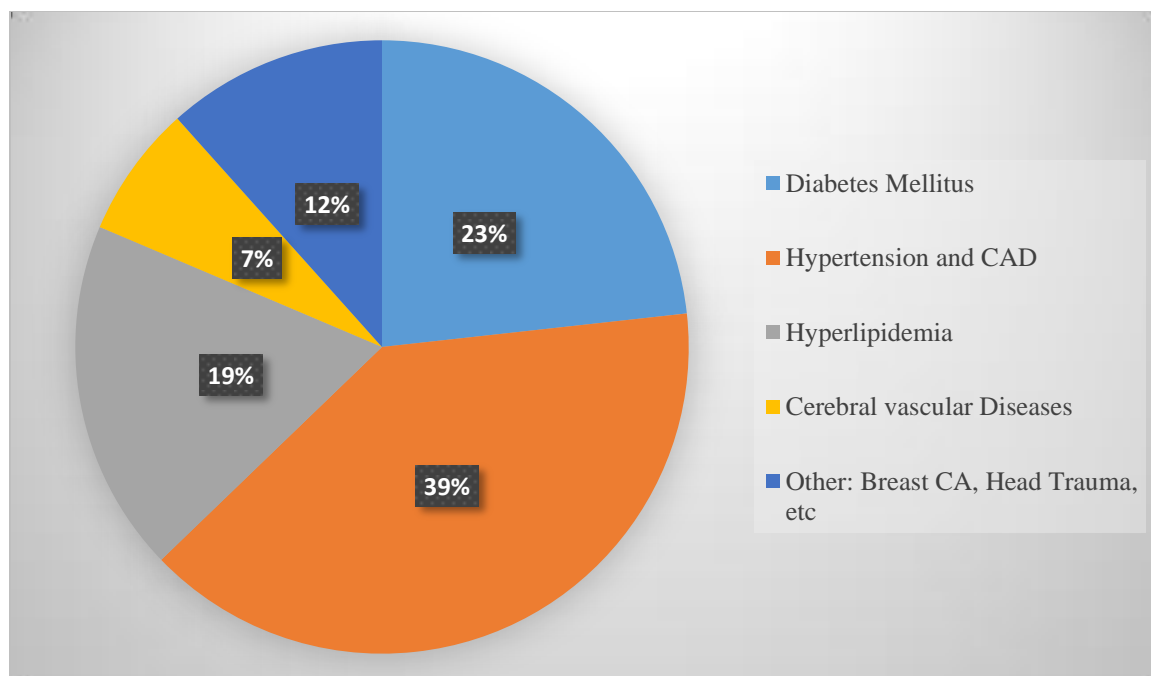


Figure 5. Comorbid conditions of participants.

Characteristics of the Participants

All of the participants met inclusion criteria for participation in the study. Each participant willingly volunteered to be part of the study. The demographic information was collected after each participant signed the consent form. Each participant chose a pseudonym to maintain confidentiality of the participant. All of the participants consented to participate in the study by signing their names on the consent form except **Tata, Calvin, Ginette, and Rose**. This section provides a brief description of each participant in the study.

Tata. **Tata** is in the age range of 61-70 years. She is married and has five adult children. **Tata** is now retired but was a merchant/vendor when she was younger. She had no formal schooling and gave consent verbally and by signing an X on the consent form. **Tata** is Catholic and has been living in the United States for the past 3 and 1/2 years. She lives with her sons. **Tata** denied being diagnosed with MCI. She communicated that she has problems with her memory. **Tata** has been in the hospital five times in 2014 and has been back and forth in the hospital since 2014. Currently she has end-stage renal disease and is receiving hemodialysis. She has hypertension (HTN) and diabetes mellitus (DM). **Tata** reported that her primary care physician wants her to take medications to improve her memory.

Calvin. **Calvin** is a male between the ages of 80-89 years old. He described himself as a “single guy” who is currently retired but explained his occupation as a dishwasher. **Calvin** had no formal education and verbally consented to the study by signing an X on the consent form. He described himself as a Catholic. **Calvin** migrated to the United States in 1971, meaning he has been living in the United States for 45 years. He subleases an efficiency apartment from someone. **Calvin** indicated he has not been officially diagnosed with MCI.

Ginette. **Ginette** is a female between the ages of 61-70 years old. She is single. **Ginette** has three adult children. She described her occupation as a merchant/vendor. **Ginette** had no formal education and verbally consented to the study and signing an X on the consent form. She is of Catholic faith. **Ginette** has been living in the United States for 6 years. She lives with her daughters and their families. **Ginette** explained that she has not been officially diagnosed with MCI but she has hypertension.

Rose. Rose is a female between the ages of 71-79. She indicated that her husband is deceased. **Rose** has two adult children. She enjoys gardening fruits and vegetables. **Rose** described her gardening as a very significant part of her life. She is retired currently but would love to find work. **Rose** had no formal education; consequently, she verbally consented to the study by signing an X on the consent form. **Rose** mentioned that she attended the alphabetization program in Haiti, but she could not learn since her memory was worsening. Alphabetization is an educational system to teach older adults how to read and to write. **Rose** described herself as a Catholic. She migrated to the United States 6 months ago. **Rose** lives with her daughter and her family. She communicated that she has not been officially diagnosed with MCI, but she experienced the memory problem 3 months ago while she was in the hospital. **Rose** communicated that the memory has not returned to baseline.

Christiane. Christiane is a male in the 71-79 age range. He is married and has five adult children. **Christiane** indicated he worked on the land and described himself as a cultivator. He is currently retired. **Christiane** communicated he had an elementary school education. Furthermore, he described himself as both Episcopal and Baptist. He attends church services wherever it is convenient. **Christiane** has been in the United States for 27 years. He lives with his wife. **Christiane** mentioned that his primary care physician has told him he has MCI. He was in a motor vehicle accident many years ago, which caused the MCI. **Christiane** reported having chronic hypertension.

Etienne. Etienne is in the 71-79 age range. He is married and lives with his wife. **Etienne** walks with a cane secondary to the effects of degenerative osteoarthritis. He used to work in landscaping; he is now retired. **Etienne** completed elementary school

in Haiti. **Etienne** described himself as a Baptist. He has been in the United States for 23 years. **Etienne** indicated he has a history of HTN, DM, and hyperlipidemia. He answered yes to having MCI, but he has no official diagnosis.

Grace. **Grace** is in the 61-70 age range. She has been married for 49 years and is very proud of it. **Grace** is a seamstress, but she is retired. She has six adult children. **Grace** places a lot of value on education because she was never formally educated. She described herself as a Christian lady, essentially Baptist. **Grace** has been in the United States for 18 years. Her son died 5 years ago, and she is still grieving. She feels her MCI stemmed from the shock of the death of her beloved son, and she feels she has not recovered from astonishment and bewilderment. **Grace** reported she suffers from HTN and old age. She had a hernia repair surgery and affirmed she suffers from chronic pain. **Grace** feels sick most of the time. She attributed her pain and “sickness” to her sorrow related to the death of her son, but she denied depression.

Bernadette. **Bernadette** is in the 71-79 age range. She is divorced. **Bernadette** is retired from her nursing assistant job. She also worked as a housekeeper and is able to sew. **Bernadette** attended high school in Haiti. While in the United States for the past 31 years, she attended adult education classes and obtained a nursing assistant certificate. **Bernadette** is Catholic and is very active in the church. She lives alone. **Bernadette** claimed she has not been diagnosed with MCI. She expressed suffering from chronic HTN and hyperlipidemia.

Iranne. **Iranne** is in the 71-79 age range. She is a retired single Catholic female. **Iranne** used to work as a housekeeper. She had some elementary school education. **Iranne** is active in the church and referred to her Christian faith during conversations.

She has been in the United States for the past 32 years. **Iranne** did not have an official diagnosis of MCI, but she communicated that her primary care physician has started diagnostic testing for her memory problems. She reported suffering from HTN and acid reflux.

Scarlene. **Scarlene** is in the 55-60-year age range. She is married has two children. **Scarlene** is a nursing assistant. Currently, she is not working since she reported being chronically ill. **Scarlene** attended some high school in Haiti, but attended technical school in the United States. She has been in the United States for 37 years. **Scarlene** is loosely Catholic, not currently practicing. She has had MCI since her stroke and heart attack many years ago. Her memory has not improved. She has not been officially diagnosed. **Scarlene** has been hospitalized several times in the past due to heart disease, DM, and cerebrovascular disease (CVA). She has a history of hyperlipidemia and osteoarthritis (OA) as well.

Jean. **Jean** is in the 61-70 age range. He previously worked as a constructor but now is disabled. **Jean** is married. He has been in the United States for the past 32 years. **Jean** is Catholic by faith. He lives with his wife and children. **Jean** completed elementary school in Haiti. He has not been officially diagnosed with MCI but he stated, "I know my memory is going worst now." **Jean** suffers from heart disease and had heart surgery many years ago. He communicated that he has a history of HTN, DM, and hyperlipidemia.

Val. **Val** is in the 80-89 age range. He is a retired landscaper and is married. **Val** completed elementary school. He has been in the United States for the past 36 years.

Val is Catholic. He has not been officially diagnosis of MCI. **Val** reported his past medical history included HTN, DM, mixed dyslipidemia, acid reflux, and hernia repair.

Pierre. Pierre is in the 61-70-year age range. He is married with adult children. **Pierre** is working full time as a landscaper. He left Haiti 28 years when he was in high school. **Pierre** attended adult education in the United States. He is currently enrolled in a computer literacy class. **Pierre** is a Jehovah's Witness. He has never been officially diagnosed with MCI.

Gerard. Gerard is in the 61-70-year age range. He is married with adult children. **Gerard** is working full time as a truck driver. He had an elementary school education in Haiti. **Gerard** has been in the United States for 39 years. **Gerard** is Catholic. He indicated he has HTN.

Roberto. Roberto is in the 61-70-year age range. He is married with a young child. **Roberto** is working full time as a nursing assistant. He received some high school in Haiti, and he attended adult education classes to become a nursing assistant in Palm Beach County, FL. **Roberto** described himself as a Baptist Christian who has been in the United States for 30 years. He had not been officially diagnosed of MCI. **Roberto** explained he does not have any precipitating events or comorbid conditions. He indicated that he is experiencing lapses in memory, which is disturbing to him.

Marie. Marie is in the 71-79 years age range. She is a widower, who has been in the United States for over 18 years. **Marie** is a fervent Catholic who prayed during the interview. She is a retired food service worker. **Marie** completed middle school in Haiti. She has a 12-year breast cancer history. In addition, she has HTN, DM, and OA.

Pierre-Jacques. **Pierre-Jacques** is in the 80-89 age range. He is married and is retired from his truck driving work. **Pierre-Jacques** completed middle school in Haiti. He has been in the United States for about 20 years. **Pierre-Jacques** described himself as a Baptist. He reported his medical history to include HTN, DM, mixed hyperlipidemia, glaucoma, OA, and prostate cancer.

Tet. **Tet** is in the 61-70 age range. He is married with adult children. **Tet** described himself as a devout Christian who loves to play the organ and is actively involved in the music ministry of the church. He regularly attends a Baptist church. **Tet** is a retired accountant. He took the high school equivalent test and enrolled in a university in the United States. **Tet** attended music school “for a little while” in the United States as well. He has been in the United States for the past 36 years. **Tet** admitted being officially diagnosed with MCI, but he does not remember his MMSE. He volunteered his past medical and surgical history, which includes HTN, glucose intolerance, hernia repair, and repair of hydrocele.

Alourdes. **Alourdes** is in the 61-70 age range. She is widowed with five adult children. **Alourdes** is a homemaker. She was never formally educated. **Alourdes** is Catholic and has been living in the United States for about 20 years. She commented on never obtaining gainful employment in the United States. **Alourdes** lives with her sister and her family. She had not been officially diagnosed with MCI, but she is very concerned regarding her memory problems. **Alourdes** reported a medical history of HTN, DM, asthma, and mixed hyperlipidemia.

Fente. **Fente** is in the 61-70-year age range. He is married. **Fente** described his occupation as “retired from accounting.” He completed high school. **Fente** has been in

the United States for 20 years. His faith is Baptist. He has not officially been diagnosed with MCI. He indicated his medical history includes HTN, CVA, DM, and hyperlipidemia.

Antoine. **Antoine** is in the 61-70-year age range. He is married with adult children. Currently, he is involved in merchant services, but he is a tailor. He communicated that he completed high school. **Antoine** has been in the United States for 16 years. He is Baptist by faith. **Antoine** denied being officially diagnosed with MCI but complained of progressive memory problems. He indicated that he had an appendectomy a few years ago and that has been his only medical issue.

All of the interviews were conducted according to the protocol set forth for the IRB committee. The interview procedure was followed. The participants felt honored and privileged to participate in the study. It was a humbling experience for the researcher to have met all of these participants from different walks of life. Participants were unique even when some of their experiences with MCI were similar. The next section will provide an overview of the results obtained from the semi-structured interviews with the participants. These statements were clustered into meaning units or themes. The researcher then synthesized the themes identified into a description of the participant's lived experience. An overall description of the meanings and the essence of Haitians' experiences with MCI were constructed.

Themes

Theme identification is fundamentally a crucial step in qualitative research. Meaning in any phenomenon is not simple, and it is not one-directional; meaning has many layers and is multi-directional (van Manen, 1990). Some participants experience a

certain phenomenon differently than others; yet, some lived experiences are common among many of the participants. After multiple cycles of reading and rereading the transcripts, writing notes, researching the literature, journaling, listening to the recordings, and writing and re-writing, the essence of the meaning of the phenomenon was finally captured after the extensive emersion of the researcher in the data. This process consumed far more hours than initially imagined.

Using van Manen's four existential lifeworld of spatiality (Lived space), corporality (Lived body), temporality, (Lived time) and relationality (Lived human relationship), this researcher was able to conceptualize four themes and two sub-themes for this inquiry. These four lifeworlds help to guide reflections in qualitative research. Spatiality refers to our lived space; it addresses the location of where an individual feels safe and where home could be anywhere the person exists. Corporality refers to the body that allows us to be in this world. Max van Manen (1990) emphasized that we are continuously revealing and concealing ourselves to the world. Our bodily language discloses us to the world. Temporality refers to the lived time; it allows the individual to view the self on a time continuum. Lastly, relationality refers to when and where the individual connects to other humans in his or her life. There is the ever-present degree of uncertainty that exist in an individual's life (van Manen, 1990). These four lifeworlds are not dependent upon one another but are related to the overall lived experiences of the participant regarding MCI. Each theme carries a significant value of its own, yet it is the sum of the whole part of experiencing MCI for the 21 participants. The themes—*Blaming*, *Stigmatizing* with a sub-theme of *Fearing*, *Doubting*, and *Spiritualizing* with a sub-theme of *Praying*—are listed in Figure 6.

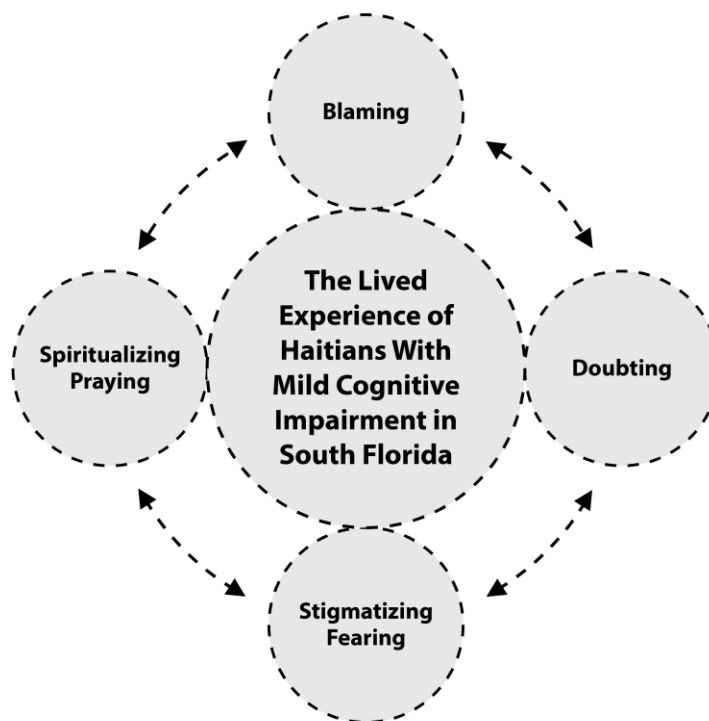


Figure 6. Conceptual representation of the lived experience of Haitians with MCI in South Florida.

Blaming

One of the themes that emerged from the data analysis is *blaming*. The themes are not sequential; they are constantly interacting with one another. According to Nudelman and Shiloh (2011), *blaming* is described as the causes or attributions to an illness. These causes or attributions could be perceived and represented as an identity, a timeline, a cure or/and control, or the consequences of the illness (Nudelman & Shiloh, 2011). *Blaming* is a gerund stemming from the noun, verb, or idiom to blame. In this study, participants used *blaming* as a way of expressing their lack of knowledge about their behavior related to MCI. They had many explanations as to why they developed MCI. Quite a few of the participants blamed their education level or the lack thereof. Most of them felt that if something was different then they would not have to experience

MCI. That “something” is a mystery or an unknown to the participants. *Blaming* can induce positive or negative behaviors in individuals and their milieus (Philip, Chadee, & Yearwood, 2014).

Tet said:

The school system in Haiti played negatively in my psyche . . . It created a lifelong trauma for me. I still remember being hit in school for stuttering and for not speaking French or for not memorizing my lessons verbatim. Music helps me to cope with it all.

Rose mentioned:

Had it not been the surgery for my fibroid, I would have been okay. After the surgery, I became disoriented. I am now getting my memory back. I think I would have been fine if I did not have the surgery.” She also blamed “thinking too much” for her slight memory problem.

Tata explained: “I don’t have an education, so I don’t know what this (meaning MCI) is called.” **Tata** continued to explain, “If someone does not have an education, they cannot be fully knowledgeable about certain things. I think this might be normal but I don’t know.”

Ginette stated: “I blame it (forgetfulness) on whatever is happening, maybe I did not sleep well, or someone made me angry then I think it is their fault that I don’t remember.”

Calvin blamed his memory problem on the memory itself. He was a man of few words but he stated, “. . .if you are doing something and you can’t remember what you

were doing... You sit and you think... you sit and you think... then it will come back to you, the memory is like that.”

Fente reported: “When you have a country whose government is running in one language and the people speak in another language that they don’t understand, what do you think will happen? You have mental problems that’s what . . .” **Fente** felt that “The lack of education and the lack of one unified language in Haiti makes the individual a weak link and it makes the society undesirable.”

Christiane blamed his kids and wife for his memory problems saying “. . . they make me so frustrated, this is the thanks I get for bringing them here (meaning the United States).” He felt that when he became angry and he remained angry, he would become more forgetful and he would experience more memory lapses.

Etienne stated, “When you are old, you are not to remember stuff, this is called (doulè granmoun, maladi granmoun) old age pain or growing pains.” **Etienne** blames his old age for his forgetfulness; he stated, “I can remember that older people used to be like this when I was young. This memory problem is nothing but me getting old.”

Scarlene blamed her heart surgery for the deterioration of her health. She said:

I know the surgery cause me to have this forgetfulness. I am getting better so I don’t worry about this memory problem much. I mean, I am not old so I won’t get Alzheimer’s. It is just the surgery. The anesthesia caused me to forget.

Jean suffered a heart attack and he had a successful open-heart surgery. He is very aware of his medical conditions. **Jean** contributed his chronic conditions as conspirators of his memory issues.

Pierre-Jacques blamed his environment particularly foods for his and his wife's decline in mental illness. **Pierre-Jacques** stated:

. . . I mean; I don't know but all these foods we eat could be causing the memory problems. We try to stay healthy and eat right. We eat more seafood to help us. I don't know what they are given those chickens. I follow the advice of the doctor. We really try to stay healthy and eat right.

Grace believed her suspicions are 100% true and that the death of her son was caused by someone through supernatural means. She said, "I know who did it but..." **Grace** was still grieving her son's death. **Grace** explained that the doctor stated that her son died of cancer, but she does not believe the diagnosis. **Grace** felt that thinking about her son's death is making her memory worst when she said, "I think and I think too much..."

Pierre laughed regarding the irony of the situation explained that he blamed his memory problems on several factors including but not limited to his wife, his age, his environment, and Haiti. He expressed the irony of his blaming but stated that "sometimes when I am in a hurry and I can't find something that I am looking for, I get so angry, I even think someone moved what I am looking for." **Pierre** started laughing, saying "this is ironic that I blame others for this."

Gerard was a man of few words but stated Lorencia was just stupid for not doing the test when she is told. **Gerard** believed in the power of the doctors. He had no issues, he stated that "I follow everything the doctor orders." He denied having MCI "...except a little forgetfulness which is due to my age."

Alourdes believed her lack of formal education causes her to be forgetful. She felt that the symptoms were deserved. **Alourdes** was very humbled to be living with her

family and felt she should not question her memory problems. She loves to watch TV, and she felt the TV is keeping her memory problems under control. **Alourdes** indicated, “nurse you know, I did not go to school, so it is normal for me not to remember things at times, but I function fine. I help them (her family). I am happy with that.”

Marie indicated her health is at fault for her memory problems. She is in remission from breast cancer. **Marie** felt her diabetes was causing some of the memory deficits. She said:

I know it is my sugar that is making me forget. I don't forget often; I recover right away from it when I do forget. Especially when the sugar is not control I get very forgetful. I feel it, you know. I know that's what it is.

Val worried about his memory problems. He felt the MCI is associated with his age, stating, “when you get old you, just you're not the same anymore. You just are a little forgetful.”

Stigmatizing – Fearing

One of the themes that emerged from the inquiry is *stigmatizing*. The gerund *stigmatizing* stems from the word stigma. Speaking about the behaviors of health care providers and students, Philip et al. (2014) demarcated stigma as a negative attitude that impacts the willingness to care for and to interact with the affected patient.

“Stigmatization therefore creates barriers to accessing important testing and treatment services” (Philip et al., 2014, p. 1236); furthermore; stigmatization refers to denouncing and wrongdoing of the person. It could create distress and negative impact on the well-being of the individual. Based on the lived experiences of the Haitians with MCI or memory problems, a person is considered to be “crazy” when they are experiencing MCI

or any mental or cognitive disorders. Many of the participants professed that in Haiti, memory problems equate with and/or are considered as craziness.

Marie was very apprehensive about a possible diagnosis of MCI or dementia. She felt her friends and family “would treat me differently.” **Marie** continued to say, “What if my kids want me to live with them or they take my house away? When you have this kind of disease, they think you are crazy?”

Jean was angry about the possible diagnosis of MCI stating, “Haitians man..., they call you names. They jump to conclusion with everything you have... .” He went on to verbalize that .

... Here (United States) you can get sick and it is normal, why then? In Haiti, every time someone is sick they jump to conclusion, and they say someone is doing it? No one in Haiti ever dies of natural causes.

Jean said this with anger. His statement is in reference to the nonverbal stigma of voodooism.

Seventeen of the 21 participants mentioned a person with memory problems would be called or considered “crazy” in Haiti. There is a malignant anxiety that accompanies the diagnosis because once diagnosed with anything, the title stays with the victim of the diagnosis. For example, **Tet** spoke about his problem with severe stuttering; the stigmatism associated with his stuttering defect almost destroyed him. **Tet** said, “I felt like I was crazy, my mom would say stay inside so no one will see you... I played music and I made it today.” **Tet** was apprehensive about a possibly developing a memory problem that could lead to the stigmatization he previously experienced. **Fente** stated:

I felt sorry for all those people who cannot handle the disease; If they were educated they would find a way to deal with this craziness. Not that people who are educated cannot get this thing (memory problem) but they can handle it better. Like me, I forget all of the time, but I won't admit it and I have ways to cover it. For example, I always make a list when I am going to the market. I use a calendar at home. No one will know I have anything wrong with my memory until I get so bad that I can't handle it anymore, but the time this happens I probably won't care what people think. I think so.

Pierre-Jacques feared possible loss of medical insurance coverage if his wife were to be diagnosed dementia. He feared the possible loss of his independence and identity. He currently drives and is very functional. He stated, "What would happen to my wife?"

Pierre-Jacques stated, "when someone has MCI, they are not crazy. They have a small memory problem."

Several participants either stigmatized Lorencia (the protagonist from the vignette) and diagnosed her immediately with dementia or they feared that they were getting dementia because of the MCI.

Rose said, "When people can't remember things that are distracted they are crazy... me I just forget a little." **Ginette** stated, "Lorencia would be considered distracted or absence in the head in Haiti."

Tata stated that her renal problems are causing her to be absent minded, but **Tata** feared that others will not understand and might labeled her crazy. "My child, they don't know, it is this cleaning blood thing that is making me that way, they might think, you know, I'm crazy. I won't tell anyone. I stay home most of the times."

Calvin stated, “Lorencia doesn’t need to do the diagnostic test, she is going crazy. That’s too bad because she is gone after that.” **Chrisiane** stated he had an MMSE done, but he cannot remember the number. He felt a label of memory disorder would be detrimental to his health and life. He does not want any more testing at this time but wants to stay healthy. **Chrisiane** said, “I am going to court for my house, I can’t be having this thing.”

Grace said “...when the memory gets worst, you become crazy, you don’t know what you are doing.” **Val** automatically diagnosed Lorecia with dementia, saying: “I know those kind of things, she has dementia. I exercise everyday, I do puzzles, every day, I go to church, I eat right so that I don’t get this thing. My memory is going.”

Etienne said, “I think, I have a the memory problem. I won’t tell anyone so that they won’t alienate me; I won’t let the neighbors know. They will only suspect that I am getting old.”

Roberto explained that his wife a mental illness, but he does not tell anymore. He explained that “she has psychiatric issues, I don’t tell anyone, not even her family” since he feared that his wife would be stigmatized for her illness.

Iranne said, “Well when you have a memory problem that means you have problems with your memory. You think too much you become distracted. Isn’t that right?” **Iranne** continued to explain, “When someone can’t remember, you have too much in your head, too much problems in your brain. You lose your head, that’s what it is. That’s what it is, you know!”

Pierre explained that:

They (people) make fun of you when you have something like that (forgetfulness), migrant Haitians men have a lack of intellectual capacity to function effectively. We just chase pretty women instead of cultivating our minds, when the women are gone, we are left speaking French and that's all.

Bernadette stated, "Lorencia has classic sign of dementia." **Bernadette** said, "...nurse, don't worry, I know she has dementia. She does not even need the test. She has dementia."

Fearing.

Fearing was a subtheme that emerged with *stigmatizing*. The fear of being stigmatized was debilitating. *Fearing* of labeling and *fearing* of illness were exhibited. *Fearing* is defined as being afraid; it is an emotion (Boudreaux, Moon, Bauman, Camargo, O'Hea, & Ziedonis, 2010). *Fearing* is associated with anxiety, which could have negative consequences. *Fearing* could be related to life changes such as the loss of social status or independence.

During the interviews and discussions, some of the participants were more forgetful than others the point where questions had to be repeated several times in different fashions. There is a malignant fear that accompanies any mental health diagnosis because once diagnosed with anything, the title stays with the victim of the diagnosis. For example, **Tet** spoke about his problem with severe stuttering, saying the stigmatism associated with his stuttering defect almost destroyed him. He said he was tormented by his schoolmates to the point where his parent had to hide him so no one would label him. He said, "I felt like I was crazy; my mom would say stay inside so no one will see you." **Tet** added, "I played music and I made it today." Since he had to stay

in the house most of the times, he felt he became very proficient at music. **Tet** feared that having a memory problem could cause similar stigmatization that he experienced when he was young. **Fente** stated:

I felt sorry for all those people who cannot handle the disease. If they were educated they would find a way to deal with this craziness. Not that people who are educated cannot get this thing (memory problem) but they can handle it better. Like me, I forget all of the time, but I won't admit it and I have ways to cover it. For example, I always make a list when I am going to the market. I use a calendar at home. No one will know I have anything wrong with my memory until I get so bad that I can't handle it anymore, but the time this happens I probably won't care what people think. I think so.

Pierre-Jacques feared possible loss of medical insurance coverage if his wife were to be diagnosed dementia. He feared the possible loss of his independence and identity. He currently drives and is very functional. He asked, "What would happen to my wife?" The researcher reiterated that she cannot give any advice on medical care but referred him back to his primary care physician for medical advice. **Pierre-Jacques** verbalized understanding. He volunteered to participate because he wanted to plead to this researcher to convey the message that "when someone has MCI, they are not crazy. They have a small memory problem." He wanted other people to benefit from this research, from his experiences. **Pierre-Jacques** pleaded to the researcher to conduct teaching or educational sessions to inform the community about MCI and Alzheimer's. He is currently strong and vibrant. **Pierre-Jacques** was making arrangements in the near future, "just in case my memory start to go, my wife and I can be taken care of." Fear of

the unknown was the driving factor for **Pierre-Jacques** and many of the participants' concerns with the memory issues.

Marie stated, "I know I have something but if I tell my kids, they might want me to move in with them." She feared losing her independence or becoming a burden to her children. **Marie** too, even after verbalizing her understanding of the process and procedure for participation, requested help from the researcher to know how to deal with this (*tèt pa la*). **Marie** prayed every day for help and felt that the researcher might be one of the people sent by God to help her. **Marie** was very apprehensive about a possible diagnosis of MCI or dementia. She felt her friend and family would treat me differently. She stated, "What if my kids want me to live with them or they take my house away? When you have this kind of disease, they think you are crazy."

Jean gets angry about the possible diagnosis of MCI, stating, "Haitians man..., they call you names. They jump to conclusion with everything you have..." He went on to verbalize that:

... Here (United States) you can get sick and it is normal, why then? In Haiti, every time someone is sick they jump to conclusion, and they say someone is doing it? No one in Haiti ever dies of natural causes.

Jean said this with anger. His statement is in reference to the nonverbal stigma of voodooism. Some Haitians believe that diseases are caused by supernatural causes; however, in the U.S., the biomedical model of health is used, not superstition as in Haiti.

Jean suffered a heart attack, and he had a successful open-heart surgery. He is very aware of his medical conditions. **Jean** contributed his chronic conditions as conspirators of his memory issues.

Several participants either stigmatized Lorencia (the protagonist from the vignette) and diagnosed her immediately with dementia or they feared that they were getting dementia because of the MCI.

Ginette stated: “Lorencia would be considered distracted or absence in the head in Haiti.” **Tata** feared that her renal problems are causing her to be absent minded, but she feared that others will not understand and might label her crazy. She feared that assessment from others. **Tata** stated: “My child, they don’t know it is this cleaning blood thing that is making me that way, they might think, you know, I’m crazy. I won’t tell anyone. I stay home most of the times.”

Calvin stated, “Lorencia doesn’t need to do the diagnostic test; she is going crazy. That’s too bad because she is gone after that.” It appeared that **Val** transferred his fears about his own predicament into Lorencia’s problems.

Val automatically diagnosed Lorecia with dementia, saying: “I know those kind of things; she has dementia. I exercise everyday, I do puzzles, every day, I go to church, I eat right so that I don’t get this thing. My memory is going.”

Roberto feared discussing his wife’s mental illness with her family since he feared they will label her wrongly and stigmatize her. “I don’t even tell her family,” he said.

Pierre said, “They make fun of you when you have a mental or memory problem.” Pierre is afraid of becoming debilitated with any illness. He said, “When you are handicapped in Haiti, they make fun of you; these kind of things don’t happen in the United States.”

Chrisiane's memory has been failing more since his car accident, which caused a traumatic brain injury many years ago. **Chrisiane** loved to talk because he feared he might not be able to converse well later if he develops Alzheimer's disease, so he talked openly and freely about anything. He said, "Nurse, I can talk to you all day, who knows I might not be able to do that later."

Doubting

From the analysis of the data evolved the theme of *doubting*. In their quest for answers and meaning, the participants wrestled with whether this is a natural phenomenon of aging. *Doubting* a gerund of the noun, and the verb to doubt is defined as, "Being unsure is an experience wherein people can no longer take themselves for granted in how they are in the world" (Phinney, 1998, p. 4). *Doubting* was exhibited when the majority of the participants exclaimed that they do not have MCI; interestingly, most participants affirmed that they have a memory issue, or as they said it in Creole, (*fè youn ti bliyè*) a little forgetfulness, which means that it is not similar to mild cognitive impairment. It appears as if that official name of the illness makes a major difference between the diagnoses for the participants. Most of the participants believed the forgetfulness is a part of growing older; therefore, the older an individual is, the more forgetful he or she becomes. The forgetfulness determines the age of the individual, according to their inferred beliefs.

Alourdes stated, "I cannot have a memory problem because I can take care of the kids and the house." **Ginette** believed since she was able to care for her grandchildren, then her memory was fine. She doubted that there is anything wrong with her forgetfulness. "I am getting older," **Ginette** said.

Rose doubted there is anything wrong with her memory; she attributed the memory problem to her recent surgery and her “thinking too much.”

Roberto claimed memory loss is not happening to him. He stated:

I am not old enough. I work with people with Alzheimer's disease that's not how they are. They don't remember their families; we have to help them with everything. What I have is not the same, I think my wife might have it though, can you help me with that?

Grace felt that, “it is not a memory problem, this forgetting things is due to thinking too much.” She stated, “if I tell the doctor, he might say it is memory problems and he would give me medications that make me worst. The medications could make me crazy.”

Calvin (peaking regarding the vignette) questioned, “What’s the use of seeking medical treatment, she is already a goner! What’s the use? Once you have it (memory problem) what it’s it!” **Calvin** doubted that any testing or treatment is going to help to improve Lorencia’s situation. He said, “She does not need to do anything about it. Just accept that she is going crazy. I think she is going crazy. I don’t know. You guys know what is happening to her.”

Val kept his activities routine to cope with the forgetfulness, yet he doubted that he is getting dementia; he was wondering what was happening with his memory. **Val** tried to be normal, saying, “I pray the rosary every day because it is something that I do all of the time. I don’t go to places that I don’t know that’s the way I function well.” Keeping his activities routine helped **Val** to cope with the forgetfulness.

Jean continued, “I don’t think anything is wrong with me, other people have this (MCI) too.” **Jean** appeared to have been in denial or in limbo; he was not sure what to think.

Tet explained that his traumatic childhood could have caused him to have memory problems today. He stated:

I am not sure but I think being teased for stuttering as a young person could have created some mental defects in me, I think it is all related. Music helps me to cope, but the torment I suffered as a child I think created a lifelong complex in me.

Fente felt all people suffer from memory problems but their education helps them to cope and to think. He verbalized:

If you are cultivated then you will be just fine, you can find ways to hide your forgetfulness; if you are not educated, you cannot hide it. I don't think anybody is normal. We all have the same memory problems; everybody forgets in their old age; it is a scientific fact."

Marie doubted whether she had MCI. She said, "I am afraid of telling the doctor, but he asks me all of the times." [She laughs], "I say no I am fine. Having Alzheimer is a hard thing, but I don't think that is what is happening with me. I think I am getting old."

Scarlene had some doubt about possible attribution of her illness to supernatural factors. She said:

I know the surgery cause me to have this forgetfulness. I am getting better so I don't worry about this memory problem much. I mean, I am not old so I won't get Alzheimer's. It is just the surgery. The anesthesia caused me to forget.

Scarlene admitted multiple comorbid medical conditions; she doubted whether her diabetes or old CVA were related her forgetfulness. She described periods where she does not feel well in the morning when she wakes up. **Scarlene** stated,

I tell you, sometimes, I feel so bad that I spend the whole day in bed, thank God my husband is nice and he helps me. I wonder if something else is not causing my memory problems, I go to church and pray all of the times for this to pass. God is good; he will help me through it (memory problem).

There are several implications associated with her statement that are not obviously clear to non-Haitians. While she is affirming her suspicion on the anesthesia as a cause of her forgetfulness, she was also *doubting* several others factors that could be contributing to her forgetfulness.

Doubting permeated from other concerns in life; these doubts about circumstantial events also radiated in the participants' mental or cognitive issues. One example is that **Chrisiane** was having marital problems; then, he started doubting whether he is having a cognitive issue or whether the memory issues were only situational. She said:

I was tested. I don't remember the number but they said I have ... I am good for now. The accident left me paralyzed and my family did not help in that sense. I think they (his family) might be making my memory worse

Pierre doubted that anything could be done to either slow the progression of any cognitive disorder; he doubted any treatment plan would work. **Pierre** stated:

In Haiti, when someone has memory problem that say the person is crazy, I don't think that is true. Here, I think they have medications that can treat the problem, why don't they treat this problem already. Maybe, they don't even understand it.

It's like my glaucoma. They could do something about my glaucoma, but no, they keep on giving me eye drops. I don't think they will do anything about my memory problem, but I am better off here than in Haiti.

Antoine doubted having “anything serious.” **Antoine** volunteered to participate in the study but denied having MCI; he said “oh, I just forget a thing or two sometimes.”

Antoine stated, “I have a little bit of a problem with my memory.”

Spiritualizing – Praying

The gerund *spiritualizing* is defined as a spiritual perspective that is embedded as a cultural norm across ethnic groups. “*Spiritualizing* is a universal human phenomenon that involves finding meaning in life, transcendence of self-boundaries, and connection with God, a Higher Being, nature and others” (Campesino, Belyea, & Schwartz, 2009, p. 73). *Spiritualizing* and *Praying*, in general, played a large role in the daily lives of most of the participants. The influences of a Higher Power, symbols, and rituals were evident in some of the conversations. It is believed that religion, spirituality, and praying supports health in old age (Rykkje, Erikson, & Rahlm, 2013). There is an increased demand for mental health services for Haitians because Haitians face with migration issues such as a need to adapt to a new culture. It would be remised if the researcher discussed the results and the role of *spiritualizing* without addressing the cultural aspect of the health care belief of Haitians in general. There is a deeply held religious belief among the participants, and it is incredible how all of them used the same logorrhea about their religious faith. Yet the uncanny verbiage exclaimed by some of the participants was remarkable. This dichotomy in *spiritualizing* was evident during some of the

conversations during the interviews. The roots of voodooism and Christianity were simultaneously present in the meekest of conversation with the participants.

Grace indicated: “My brother says he knows who killed my son, and he can revenge his death, but I am a religious person, so I cannot be involved in wrongdoing. Let God take care of it.”

Although **Grace** believed in God, she is still convinced that supernatural forces played a role in her son’s demise, saying “... I trust and believe in Christ, the Redeemer . . .” She still felt her son who she said, “they pretended, it was cancer that killed him but it was not, I know who killed him.” The nonverbal insinuation that **Grace** used was that although she was professing her love for Jesus Christ, she still believed in the supernatural involvement in her son’s death. **Etienne** spoke very optimistically when he stated: “I feel blessed among many adversities.” **Etienne** said to the researcher, “you know; we cannot talk about everything,” this reference is to the supernatural effect that should not be spoke. **Etienne** had some financial problems, and he viewed his participation in this research as “another act of God” since he also was getting the token of appreciation too; he felt it was God sent.

Ginette prayed that she did not “become like the other people that I have observed with this craziness. They become all crazy, they don’t know if they already ate, it is sad.” Additionally, **Ginette** revealed that she was no longer taking her blood pressure medications because she felt the high blood pressure is resolved. She said, “thank God! It (hypertension) is gone.” Ginette’s faith was central to her existence; she felt connected to God and the universe. She believed her HTN was resolved.

Ginette, like many other participants, believed they are themselves spiritual beings and that they are connected to the universe. They believed when they live in harmony with the greater power, everything is satisfactory including their health.

Iranne indicated she was so very religious that she wore many rosary beads around her neck. She stated, "I am testifying the glory of God." Like many of the participants, **Iranne** believed the "forgetfulness" will go away with the will of God, but she was willing to endure whatever tribulation bestowed that her. While testifying the glory of God, **Iranne** still talked about how she encountered several supernatural effects. She stated:

One day, I had this dream that something was going to happen to my friend. I took her to the church, I prayed for her. I help her. It was someone who was going to do something to her. Until today she still thanks me for helping her. She had to go to Haiti for help but she is fine now. She still calls me to thank me all of the time.

The reference to going to Haiti means that she was seeking help from either a voodoo priest or healer for ailments. It appeared that both **Iranne** and her friend concurrently believed in God and supernatural effects of man or deity. **Bernadette** completed the interview session by praying for the researcher so that this dissertation process can be successful. She hummed praise songs while walking. She appeared very happy. She sang the Haitian Flag song from her youth, the Haitian flag was on the recruitment flyer nearby when she spotted it and instantaneously started singing. She was a very proud and tenacious woman. **Bernadette** professed that, "I would not be able to be myself had it not being for the constant support of God my Savior and Redeemer."

She is now looking for a job, and she prayed that she could assist someone in need; she is a Certified Nursing Assistant.

Val worried about the increase in absentmindedness that he is experiencing. **Val** stated he prayed, he did jigsaw puzzles, and he recited the Holy Rosary daily to keep his brain active. He performed physical activities and weight training exercises on a regular basis. "I am afraid of what might come, but I trust in God that I will remain healthy." **Val** prayed as a way to remain healthy physically and mentally while he is experiencing lapses in his memory.

Religion was a part of their *spiritualizing*. The first word most of the participants spoke of was that through their spiritual life they were able to endure several adversities. Most felt *spiritualizing*, and their church was synonymous. Deep religious faith fostered feeling of well-being in the participants (Nabolsi & Carson, 2011). The majority of the participants cited praying as a regular ritual they performed prayers routinely.

Marie exclaimed that she practically lived at the church. "I pray for other people and for myself. You know prayer is like a meditation; I always feel good when I go to church." **Tet** plays the organ in his Baptist Church. **He** stated: "I find solace in playing music. Music helps me to cope with everything. I play mostly for the church. I play in other places too; playing music calms me down, I think clearly when I play." **Tet** further explained that his traumatic childhood could have caused him to have memory problems today:

I am not sure but I think being teased for stuttering as a young person could have created some mental defects in me; I think it is all related. Music helps me to cope but the torment I suffered as a child I think created a lifelong complex in me.

Scarlene had some doubt about possible attribution of her illness to supernatural factors, saying:

I know the surgery cause me to have this forgetfulness. I am getting better so I don't worry about this memory problem much. I mean, I am not old so I won't get Alzheimer's. It is just the surgery. The anesthesia caused me to forget.

Scarlene reported multiple comorbid medical conditions; she questioned whether her diabetes or old CVA was related her forgetfulness. **Scarlene** confessed of following her doctor's orders, but she reported her Accucheck and Blood Pressure readings are still not controlled. She described periods where she does not feel well in the morning when she wakes up. **Scarlene** stated:

I tell you, sometimes, I feel so bad that I spend the whole day in bed, thank God my husband is nice and he helps me. I wonder if something else is not causing my memory problems, I go to church and pray all of the times for this to pass. God is good, he will help me through it (memory problem).

There are several implications associated with her statement that are not obviously clear to non-Haitians, **Scarlene** suspected supernatural involvement into her illness.

Jean explained, "I don't think anything is wrong with me, other people have this (MCI) too." **Jean** commented, "I go (church) all of the time" **Jean** was angry about the possible diagnosis of MCI, stating: "Haitians man..., they call you names. They jump to conclusion with everything you have..." He went on to verbalize that "... Here (United States) you can get sick and it is normal, why then? In Haiti, every time someone is

sick they jump to conclusion, and they say someone is doing it? No one in Haiti ever dies of natural causes.” **Jean** was angry. He was referring to the practice of voodoo.

Pierre attended religious services on Saturdays since he is a Jehovah’s Witness, and he said, “Oh of course, I go to temple regularly.” Spirituality is a part of his life. **Pierre** strongly believed in the mind-body-spirit connection. He confessed that he ate well, exercised, and prayed regularly.

Gerard stated “after God is doctors.” **Gerard** was not very talkative but proclaimed his love for God stating, “...yeah I pray regularly.”

Pierre-Jacques said “... my wife is sick so I don’t go to church all of the times but I go to church once a month ... the first Sunday of the month to receive communion” Although he did not attend services regularly, he felt his spiritual life was very important for his well-being.

Fente nonchalantly mentioned, “I attend church all of the time.” Church attendance did not seem as important as other subjects. **Fente** preferred to talk about the state of the country of Haiti or how the government is failing all Haitians. He felt strongly that a systematic change needed to occur in the Haitian way of life starting with changing the French language of Haiti to English. **Fente** attended social clubs as means of “preserving my mentation and sanity.”

Praying

Praying is used as a subtheme of *spiritualizing* since religiousness cannot be separated with spirituality and *praying*; spirituality fosters dignity in the individuals (Rykkje et al., 2013). *Praying* is seen as a conversation with God or a Higher Power. Unantenne, Warren, Canaway and Manderson (2013) stated, “Various spiritual and

religious practices such as *praying*, spiritual healing, yoga, and t'ai chi provide people with mental and emotional support and are distinct from healing practices informed by formal religions" (p. 1147). The authors continued to write that "prayer" is said to be able to help the person "to make sense of their suffering and/or to manage their health" (Unantenne et al., 2013, p. 1147).

Praying was one of the concepts reflected by the participants in most of the interviews. **Grace** indicated, ". . . I trust and believe in Christ, the Redeemer . . ."

Ginette prayed when she could not remember. She described getting frustrated and angry; consequently, she would pray to have better and calmer days. **Ginette** prayed that she "do not become like the other people that I have observed with this craziness. They become all crazy; they don't know if they already ate; it is sad." Additionally, **Ginette** revealed that she is no longer taking her blood pressure medications because she felt the high blood pressure is resolved. She said, "thank God!; it (hypertension) is gone."

Rose reported that she prays most of the day. The more she forgets, the more she prays because praying calms her down, and she can recall her thoughts. **Rose** said, "Jesus is my life, he is the light of the world, he is my God." She added, "I cannot do anything without him. If I forget, how will I help the others? God helps me every day."

Chrisiane said, "God is my strength and my refuge." He goes to church all of the times, at times more than once a day. When he cannot remember, he prays. He said, "it (the memory) always comes back to me after I pray." **Etienne** spoke very optimistically when he stated, "I feel blessed among many adversities." He said to the researcher, "you know; we cannot talk about everything." This reference is to the supernatural effect that should not be spoken of. **Etienne** had some financial problems, and he viewed his

participation in this research as “another act of God.” Since he also is getting the \$25 dollar Walmart gift card as a token of appreciation too, he felt the money was God sent. **Iranne** indicated she is so very religious she wore many rosary beads around her neck. She stated, “I am testifying the glory of God.” Like many of the participants, **Iranne** believed the “forgetfulness” will go away with the will of God, but she was willing to endure whatever tribulation comes her way.

Bernadette completed the interview session by praying for the researcher so that this dissertation process can be successful. **Bernadette** professed that, “I would not be able to be myself had it not being for the constant support of God my Savior and Redeemer.” She is now looking for a job, and she prayed that she could assist someone in need; she is a Certified Nursing Assistant.

Val worried about the increase in absentmindedness that he is experiencing. **Val** stated he prayed, he did jigsaw puzzles, and he recited the Holy Rosary daily to keep his brain active. He performed physical activities and weight training exercises on a regular basis. “I am afraid of what might come, but I trust in God that I will remain healthy.” **Val** prayed as a way to remain healthy physically and mentally while he was experiencing lapses in his memory. **Scarlene** stated:

I tell you, sometimes, I feel so bad that I spend the whole day in bed, thank God my husband is nice and he helps me. I wonder if something else is not causing my memory problems, I go to church and pray all of the times for this to pass. God is good, he will help me through it (memory problems).

Jean commented, “I go (church) all of the time.” **Pierre** attended religious services on Saturdays since he is a Jehovah’s Witness; he said, “Oh of course, I go to temple regularly.”

Gerard stated “after God is doctors.” **Gerard** was a man of few words but proclaimed his love for God, stating “...yeah I pray regularly.” **Pierre-Jacques** said “... my wife is sick so I don’t go to church all of the times but I go to church once a month ... the first Sunday of the month to receive communion.” Finally, **Fente** nonchalantly mentioned, “I attend church all of the time.”

The majority of the participants cited praying as a regular ritual they performed routinely. **Tata** prayed that she might be able to return to Haiti to see the rest of her family. She stated: “I pray that I can go home one day before I die...” **Roberto** mentioned he was Baptist. **Roberto** worried about the fate of his wife and stated, “I pray that she can find some help with her memory problems. She is so young. We have a small child.” **Marie** exclaimed that she practically lived at the church, explaining, “I pray for other people and for myself. You know prayer is like a meditation; I always feel good when I go to church.” **Tet** played the organ in his Baptist Church. **He** stated, “I find solace in playing music. Music helps me to cope with everything. I play mostly for the church. I play in other places too, playing music calms me down, I think clearly when I play.” **Alourdes** announced that she prayed daily and the church provides her an occasion for socialization. She stated, “They (fellow church members) give me a ride to the church and to prayer meetings; I don’t drive.” **Antoine** worried about forgetting important work-related appointments, which could affect his compensation, so he stated, “I pray a lot.”

Connection to a Theory

The themes that emerged from this inquiry revealed an appropriate connection to the Reconceptualized Uncertainty in Illness Theory (RUIT). This level of theory development is middle range, which applies readily to nursing practice and research. The uncertainty in illness theory (UIT) was developed by 1988 by Merle Mishel. Mishel was born 1939 in Boston, Massachusetts. She graduated in 1961 with a bachelor of arts from Boston University. In 1966, she graduated with Master of Science in Psychiatric Nursing from University of California. She graduated in 1980 with a Master's of Arts, and a doctorate degree in social psychology from Claremont Graduate School in California. During her dissertation research, Mishel developed the Mishel Uncertainty in Illness Scale (MUIS). Mishel and others have conducted several studies using her theory and her tool (Mishel, 2010).

The evolution of uncertainty in illness theory began in the late 1970s, when there was very little information known about the phenomena of uncertainty in illness. There was a lack of systemic investigation of uncertainty with uncertainty being the perceptual variable that is influencing the appraisal of illness-related events. This theory was originally developed as UIT; the MUIS was developed, then the RUIT was later developed. The Reconceptualized Uncertainty in Illness Theory (RUIT) was developed in 2003 to address the limitations of the uncertainty in illness theory relating to changes in illness that are occurring over time. During the conception of the UIT, Mishel used works on stress and coping from Richard Lazarus and Folkman. She utilized existing models from Warburton regarding information processing, and she used Budner's research about the effects of a person's personality on their tolerance level of ambiguity.

The UIT has three major themes: antecedents of uncertainty, appraisal of uncertainty, and coping with uncertainty. The Uncertainty of the Illness becomes the driving force and the illness itself is accepted as reality (Mishel, 1990). The illness causes uncertainty to spread into the individual's life, and it disrupts the individual's perception and reality. Uncertainty regarding a medical phenomenon and the duration of the phenomenon are great psychological stressors to the individuals affected. Viewing uncertainty as a neutral state until it is appraised and valued, Mishel explained that with continuing uncertainty, the person develops a new view of life and embraces multiple contingencies as preferred and possible (Mishel, 2010). The critical social theory and the chaos theory guided the reconceptualization of the uncertainty in illness theory (Mishel, 2010).

According to Mishel (2010), the Reconceptualized Uncertainty in Illness Theory: was developed to address uncertainty during the diagnostic and treatment phases of an illness or an illness with a determined downward trajectory ... It proposes that uncertainty exists in illness situations that are ambiguous, complex, unpredictable, and when information is inconstant or not available. (p. 617-618).

Chapter Summary

This chapter provided a narrative account of the lived experience of Haitians with MCI in South Florida. The significant findings of the inquiry were presented. The demographic information was presented regarding the 21 participants. A deeper understanding of the daily lives of the participants' lived experiences was captured through the phenomenological descriptions. The researcher attempted to elucidate the meaning ascribed by the participants. Guided by Max van Manen's (1990) phenomenological method of inquiry and analysis, this investigation provided the

researcher with rich and thoughtful descriptions and an increased understanding of what it is like for Haitians to experience MCI in South Florida.

The data analysis synthesis revealed four prominent themes and two sub-themes from the experiences of the participants: *blaming*, *stigmatizing - fearing*, *doubting*, and *spiritualizing - praying*. The Reconceptualized Uncertainty of Illness Theory, which provides meaning to the themes that emerged from the participants' descriptions, was briefly presented and will be discussed in Chapter Five. The discussion and conclusion of this phenomenological inquiry will be presented in Chapter Five.

CHAPTER FIVE

DISCUSSION AND CONCLUSION OF THE INQUIRY

The purpose of this phenomenological inquiry was to explore the lived experience of Haitians with MCI living in South Florida. The significance and the meaning of this inquiry were explored to reflect the multiple truths and realities for each participant. With phenomenology, the words of the participants could be interpreted differently based on the lived experiences of the researcher; however, despite the words chosen by the researcher to describe and explain the participants' lived experiences; the essence of the lived experiences of the participants will prevail. An interpretative analysis of the themes that emerged from the study will be presented and connected with published literature, poems, and music. A discussion of the relationship between the findings of the inquiry and the Reconceptualized Uncertainty of Illness Theory will be presented. The implications of the study for nursing education, practice, research, health and public policy will be discussed along with the limitations and strengths. Recommendations for future studies will be presented.

Exploration and the Meaning of the Study

The overarching question underlying this inquiry is, "What is the lived experience of Haitians with MCI living in South Florida?" A literature gap existed to support the justification for this inquiry. Haitians in South Florida experience MCI, but there is a lack of intergradation of this disenfranchised cohort into research studies. Hermeneutic phenomenology guided by Max van Manen was used to illuminate and understand the rich data obtained from the semi-structured interviews. Phenomenology as a method of inquiry and a philosophy facilitated the research design and the descriptive interpretation

of this inquiry. The researcher was able to discern meaning and the essence of this phenomenon by listening to the voices of the Haitians with MCI as they told their stories of life with MCI. The narratives provided a clearer understanding of life with this phenomenon of uncertainty. The researcher engaged in various activities, which involved journaling and discovering expressions of meaning through music, literature, films, and poems. The implications of words in conversations were reviewed repeatedly, and the verbatim transcriptions were read and reread while searching for the essence of this phenomenon. The conceptual representation of the lived experiences exposed the four major themes with their sub-themes from the inquiry: *Blaming, Stigmatizing - Fearing, Doubting, and Spiritualizing - Praying*.

Interestingly, *praying* was one of the concepts that was reflected in the conversation of the majority of the participants. In one form or another, each participant verbalized their ways of coping with mild cognitive impairment or a little forgetfulness, as they perceived it. The researcher was able to re-live each interview through her notes, transcriptions, and listening to the interviews, thus ensuring that she had described the participants' stories accurately. Saturation was reached when the ideas and language became repetitive and recurring during data collection. Despite saturation at 15 participants, the remaining six participants requested to participate in the study to verbalize their opinions on MCI. The conclusion related to the essence of the lived experience of the 21 participants has been shared with detailed narratives to support the findings.

The soundness or rigor of this qualitative inquiry is judged by credibility, authenticity, dependability, confirmability, and transferability (Lincoln & Guba, 1994).

Credibility is achieved by ensuring that the results are credible or believable and that the interpretations are true. This is accomplished via prolonged engagement, which is the time this qualitative researcher spent in the field collecting data, observing, and interviewing to gain in-depth knowledge. The continuous peer review of the data, analysis, and interpretations by members of the dissertation committee who are experts in the field also ensure credibility of the data (Creswell, 2013). To confirm authenticity, the researcher included all data from which conclusions were made; she sought professional feedback, employed semi-structured interviews with open-ended questions, and used detailed narratives to support findings.

Dependability is synonymous with the reliability of the study. It involves auditability of the data collection and data analysis process. This was achieved by describing in detail the sampling procedure, and the data collection procedure was described; consequently, others may read and be able to evaluate the method.

Confirmability is a measure of how well the study's discoveries are supported by the data collected. Confirmability is established by paper trail and by linking the words of the participants and with the discoveries (Lincoln & Guba, 1994). Transferability means the results of this inquiry can be transferred and reproduced. The researcher ensured transferability by providing a detailed description of the study from purposive sampling to data analysis to provide a "paper trail," thereby providing opportunities for replication or to determine transferability of results (Lincoln & Guba, 1994).

Qualitative researchers are considered as the instruments of the research study; therefore, they can be easily biased. To maintain the integrity of qualitative studies, the studies must ensure trustworthiness. Trustworthiness can be achieved when the findings

reflect the meanings as described by the participants as closely as possible. The aim of trustworthiness in any qualitative inquiry is to support the research findings (Lincoln & Guba, 1994). Epoche or bracketing is used so that the researcher may deposit his or her presuppositions and thus enters into the world of the participant. The audio-taped interviews were transcribed verbatim by the researcher. To capture and understand the essence of the lived experience of the participants, the researcher listened to the interviews, read, and rereading the transcripts together with the reflective notes and made highlighted notes, and then the codes and themes emerged.

Interpretative Analysis of the Findings

The researcher read and reread the transcripts several times and looked for sentences that capture the meanings of the experience. The text was reviewed line by line, and sentences were highlighted that captured the meanings of the experience. The researcher examined the margin notes to identify categories or codes to encrypt the transcripts. The transcribed interviews were scrutinized. After reviewing the data in detail, the researcher classified and explained the many themes and subthemes that emerged from the data. The participants were contacted for a second interview to confirm details of the transcripts – member check. Literature reviews, prayers, music, and poems supported the themes. The relationship between the findings of this study and the RUIT was established after reviewing the construct of the theory and the data obtained. Other grand and middle range theories were also reviewed but the RUIT was the best fit for the findings. This qualitative inquiry highlighted the lived experience of Haitians living with MCI in South Florida. The data analysis revealed four major themes and two sub-themes regarding the essence and meaning of the lived experience of the 21

Haitian participants living with MCI in South Florida. *Blaming, Stigmatizing - Fearing, Doubting, and Spiritualizing - Praying* are discussed below.

Blaming

Blame it on the rain that was falling, falling

Blame it on the stars that shine at night

Whatever you do

Don't put the blame on you

Blame it on the rain, yeah-yeah

Cause the rain don't mind

And the rain don't care

You got to blame it on something

You can blame it on the rain

You can blame it on the rain

(Genius.com, 2016)

During the 1980s, Milli Vanilli released “Blame it on the Rain” (A shorten version of the lyric of the song is presented above to illustrate a point). The lyrics seem appropriate for the theme of *blaming*. As human beings, we strive for self-preservation; however, no matter how committed humans are regarding our personal responsibilities about our health, there are some age-related illness that cannot be prevented (Harris et al., 2015). Humans can delay the process of certain illnesses by choosing to be healthy; however, as human beings age, we do not decide to remain younger and healthy (Harris et al., 2015). The natural process of aging occurs automatically, and during this process, some age-related illnesses occur. Harris et al. (2015) wrote “sometimes, no matter what

you do, disease is hereditary” (p. 382). The article pointed that that since you cannot blame an apple for rotting and the flower for wilting, people should not be blamed for aging and becoming ill. The participants in this inquiry did just that. In an effort to protect and preserve themselves, they blamed everything around them for their memory problems. *Blaming* has been an ongoing topic in nursing philosophy and practice. In the context of this study, *blaming* meant the participant was attempting to escape his or her reality. He or she was *blaming* his or her situation as a survival technique. When someone perceives an event as unfair, the person’s peace of mind will be undermined, which raises feelings of anger and anxiety (Nudelman & Shiloh, 2011). The sentiments of anger and anxiety were directly expressed when **Ginette** stated:

I get mad when I cannot remember what I was going to do or what I am doing. I have to rest to remember what I was going to do. I get so angry. I blame it on whatever is happening, maybe I did not sleep well, or someone made me angry then I think it is their fault that I don’t remember. It (forgetfulness) is happening more now. I just don’t understand it.

Some of the participants blame their memories and their ages for deceiving them. As **Etienne** tried to understand the cause of his memory problem, he attributed his syndrome to his wife and kids who disagree with him at this time. He stated:

I don’t know why I brought them here (United States), they are nothing but trouble, how? Can you believe it that I am paying for the house but I cannot live in peace in it? All this unrest does not make me well; everyone knows that you must be peaceful in your home to be in good health.

Etienne felt remorseful about having his family in the U.S. with him. He felt they were a source of aggravation to himself. He, in turn, felt the aggravation or lack of peace of mind causes memory problem or MCI.

“Believing that a certain cause has a particular strong influence on disease development may generate risk perceptions, which in turn may elicit specific coping efforts and preventive behaviors” (Nudelman & Shiloh, 2011, p. 675). **Tet** stated:

I go to the gym when I am off (work) with my friends, and we hang out at the gym, I know staying healthy will help me in everything I do believe so, I do everything I can to keep healthy.

Tet felt that if he did not exercise and stay healthy, then he would develop memory problems. **Fente** blamed the Haitian educational system for his poor memory. He stated:

How can a country function like that ... when you are growing up, you see everybody trying to speak a language that makes you crazy. Those of us who are educated are better. The rest are in misery. That’s not how a country is to run; that’s why the country is in such bad shape. We should have one uniform language.

Pierre blamed the poor lighting system in Haiti for his poor eyesight. He expressed, “How can my eyes not be bad? I used to draw at night with little lamps, these things destroyed my eyesight.” At times, there was not a clear linkage between the participants’ perception of the cause of MCI and the situation that they were *blaming* for the MCI as exhibited by **Pierre’s** statement above. Pierre also felt a little forgetfulness is a part of aging when he said “...you forget a little when you’re getting older, it is a normal part of aging.” He continued “sometimes when I am in a hurry and I can’t find

something that I am looking for, I get so angry, I even think someone moved what I am looking for.” **Pierre** started laughing, saying, “This is ironic that I blame others for this.”

Tet felt that the educational system of Haiti caused him to suffer a good deal of humiliation from his school friends. He shared:

Because they made fun of me because I was different—I stuttered. The stuttering is now better. I had to memorize everything without really comprehending anything; you know ... This system has to change. In addition to my stutter, which was bad, I could not understand anything in school. I became very shy. I did not have many friends. I was miserable, I think all those caused me to have this memory problem now.”

Alourdes indicated, “nurse you know, I did not go to school so it is normal for me not to remember things at times, but I function fine. I help them (her family). I am happy with that.”

Marie felt her diabetes is causing some of the memory deficits.

I know it is my sugar that is making me forget. I don’t forget often; I recover right away from it when I do forget. Especially when the sugar is not control I get very forgetful. I feel it, you know. I know that’s what it is.

Val worried about his memory problems. He felt the MCI is associated with his age, saying, “When you get old you, just you’re not the same anymore. You just are a little forgetful.” Judgement can be ascribed to any reasons for a phenomenon, the individual was usually ashamed of any cognitive disorder or illness; therefor, the individual assigned blame to whatever he/she believed would be acceptable to society. **Val’s** feelings were validated by Philip et al. (2014) who conducted a study to examine

health care students' reactions towards HIV patients; they stated "departure from social norms illicit negative evaluations and emotions about the patient with HIV and also inhibits social interaction with him/her" (p. 1236).

Tata blamed "thinking too much" about her situation for her forgetfulness. **Rose** stated "I think of the people I left in Haiti, I feel sad, I start thinking too much then my memory is not the same. I don't remember well after that." **Rose** also blamed her anesthesia from her recent surgery for her forgetfulness.

Calvin said:

You lose our consciousness so you cannot remember. You are not aware any more. You just can't remember. What do you do to stop it? You sit and you think ... you sit and you think ... then it will come back to you, the memory is like that.

Christiane was very frustrated and attributed his memory problems to relationship problems with his wife and kids. **Christiane** felt the family distracted him "a great deal to the point where my memory is getting bad." **Gerard** denied having MCI "...except a little forgetfulness, which is due to my age." **Grace** blamed the death of her son on someone through supernatural means. "I know who did it but..." she was still grieving her son's death and was sad about his passing.

Pierre-Jacques blamed environmental factors for his slight forgetfulness. **Pierre-Jacques** said, "I take vitamin B12 every day to help me, I exercise, and I eat right. My memory is not bad at all but we just don't know what they are putting in our foods."

Scarlene partially blamed her recent bout of illness on supernatural events. She felt she was lucky that her husband was present to witness the onset of her CVA, saying, “otherwise I would not have noticed it (stroke). **Scarlene** stated:

I thank God for my husband; he was home. I woke up and I went to the bathroom, I was just getting ready for work, I did not know anything was wrong, I woke up like that, I did not see that my face was lump-sided, but in my dream, I was fighting with something last night.

Harris et al. (2015) explained that that certain aspects of the person’s life cannot be controlled no matter what the person does. For instance, if someone is genetically predisposed to heart disease, certain lifestyle choices can delay the disease progression, but if the individual lives long enough, eventually the disease process will surface. Harris et al. (2015) discussed the Health Charity Video campaign “Make Health Last,” which was geared to help Canadian citizens to take responsibility for their health choices, to avoid health risks, to inform themselves about health issues, and to adapt a healthy lifestyle. Although the majority of the responses were seen as positive, some of the respondents felt like they were being attacked as if they did something wrong to cause themselves to be sick; some respondents argue the fact that age alone and hereditary will play a role in people’s life. It is a natural fact that humans attribute blame in situations; unsurprisingly, *blaming* occurs in many interactions in health care. Figure 7 presents a poem on blame that seems apropos to the theme of *Blaming*.



Figure 7. Poem on blame, author unknow.

Harris et al. (2015) reported that with minority groups in Canada, personal responsibility has become the dominant discourse to aging and health. Adamson (2001) explained in her study that most of the participants were familiar with the condition of dementia, but they used different terms to describe the disorder. She continued to explicate that difficulties in relationships might arise when, due to a lack of understanding of the condition, blame is assigned unjustly. Nurses play an integral role in the patient interaction and teaching. The role of nursing as a profession in this inquiry would be to assist the individual to identify reasons for and against the blame and to help the patient understand the disease process. Evidence-based practice and research inquiries should provide the tools needed to assist the nurses. The nursing profession promotes the well-being of individuals and societies.

In connection with the RUIT, *blaming* is considered an antecedent for MCI. *Blaming* falls into the stimuli frame, which is the threat perceived by the individual. The cues of the event are located in that frame. The experiences of MCI are located in stimuli

frame. *Blaming* was used as a tool for the participants to justify their current circumstances. Factors such as lack of formal education, teasing in school, and lack of family support all affected the perception of the individuals. As discussed in Unson et al.'s (2015) study, the antecedents were feelings of resentment, family conflict, lack of social support and medical support, and financial strains. These feelings are reflected in this inquiry in that the participants blame certain aspects of the MCI on their environments; they also blamed society in general for stigmatizing memory problems. The participants seem to be able to cope better when they are able to blame the memory problem on someone or on something as supported by Harris et al. (2015)

Stigmatizing – Fearing

In Haiti, a person with any mental illness could be viewed as “crazy, stupid, possessed, or labelled non-functional or worthless” (Cianelli et al., 2013, p. 529). The perception of possibly having or getting dementia when the individual is forgetful causes fear and anxiety in the whole social environment (Boudreaux et al., 2010). Difficulties are always anticipated in people with the dementia, thus explaining the fear of dementia or any memory problem (Henry et al., 2009). This researcher feels, although not expressed, that many of the participants were at the point where formal medical testing was warranted. Some participants felt their healthcare providers would not help them with the memory problem since these participants believed the providers viewed the memory problems as normal. The researcher did not discuss any recommendations with the participants; however, if the participant requested information about their memory problems, they were referred to visit their PCP. It is pragmatic to disclose that the *stigmatizing* and *fearing* are strongly connected. There was no clear mention of

stigmatizing without the inclination of *fearing*. There was always a connotation being made between the theme of *stigmatizing* and *fearing*. However, although *fearing* existed, it occurred secondary to the primal apprehension regarding stigmatization. *Stigmatizing* can be done from different vantage points (Link & Phelan, 2001).

As communicated by the chorus of this very famous Haitian poem/song

Choucounè:

English: “When I think of this. It brings me such pain. Ever since that day.

Both my feet in chains. When I think of this. It brings me such pain. Both my feet in chains.”

Creole: “Ti zwazo nan bwa kit’apé kouté (x2). Kon mwen sonjé sa. Mwen genyen lapen. Ka dépi jou-sa. De pyé mwen nan chen. Kon mwen sonjé sa.

Mwen genyen lapen. De pyé mwen nan chen.”

Stigmatism causes pain and duress to individuals from different levels of society or all walks of life. Oswald Durand wrote the poem in 1883 about his beautiful lover. Choucounè, the subject of the poem, fell into hard times and became insane. Choucounè was ridiculed regarding her mental illness. She had to beg for money and food to sustain her survival. Choucounè died at the age of 41. The poem was turned into a song by Michel Mauleart Monton and performed in Port-au-Prince in 1893. Based on the influences of the foreigners to Haiti, the song became very well-known *Yellow Bird* song, that is performed everywhere as a Caribbean song (Chery, 2013). The irony of this poem/song is that the subject of this beloved poem/song died of insanity and people made fun of her insanity. The stigma of mental illness is a satire of even our prized possessions. The poem *Choucounè* is listed below in English courtesy of Gage Averhill,

written by Oswald Durand, and translated from the Creole by Dady Chery (2013). The poem is long so only a few stanzas are presented to illustrate the connection to the theme.

Choucounè Poem/Song

1. Behind a thick cactus grove
 Yesterday I found my Choucounè
 Oh! That smile when she saw me
 I said "Heaven, what beauty!"
 I said "Heaven, what beauty!"
 She said, "Dear, do you think so?"
 (Chorus:) Little bird, who listened deep in
 these woods (2X)
 When I think of this
 It brings me such pain
 Ever since that day
 Both my feet in chains
 When I think of this
 It brings me such pain
 Both my feet in chains
2. Choucounè is a marabout,
 Eyes as bright as candlelight
 Her breasts ever so perky
 Ah! If Choucounè had been true!
 Ah! If Choucounè had been true!
 We stayed and talked a long while
 (Chorus:) All the birds looked so happy in
 these woods (2X)
 Better forget this
 The pain is too great
 Ever since that day
 Both my feet in chains
 Better forget this
 The pain is too great
 Both my feet in chains
 (Chorus:) Little bird, who heard every word
 she said (2X)
 If you think of this
 It will make you sad
 Ever since that day
 Both my feet in chains
 If you think of this
 It will make you sad
 Both my feet in chains
 (Chorus:) Is all lost, dear little bird of these
 woods (2X)
5. Young white fellow came around
 Trim red beard on his pink face
 Pocket watch and hair of silk
 My troubles, he brought them all
 My troubles, he brought them when
 He found my pretty Choucounè

1. Dèyè yon gwo touf pengwen
 Lot jou mwen kontré Choukoun
 Li souri lè li wè mwen
 Mwen di : « Syèl a la bèl moun »
 Mwen di : « Syèl a la bèl moun »
 Li di : « Ou trouve sa chè ? »
 (Chorus:) Ti zwazo nan bwa ki t' apé
 kouté (x2)
 Kon mwen sonjé sa
 Mwen genyen lapen
 Ka dépi jou-sa
 De pyé mwen nan chen
 Kon mwen sonjé sa
 Mwen genyen lapen
 De pyé mwen nan chen
2. Choukoun sé yon marabou
 Jé li klére kon chandèl
 Li genyen tété debou
 A si choukoun té fidèl
 A si choukoun té fidèl
 Nou rété kozé lontan
 (Chorus:) Jis zwazo nan bwa té parèt
 kontan (x2)
 Pito bliyé sa
 Sé two gran lapen
 Ka dépi jou-sa
 De pyé mwen nan chen
 Pito bliyé sa
 Sé two gran lapen
 De pyé mwen nan chen
 (Chorus:) Zwezo te tandé tout sa li té
 di (x2)
 Si ou sonjé sa
 Yo dwé nan lapen
 Ka dépi jou-sa
 Dé pyé mwen nan chen
 Si ou sonjé sa
 Yo dwé nan lapen
 Dé pyé mwen nan chen
 (Chorus:) Eske tout sa fini, ti zwazo
 nan bwa (x2)
5. Yon ti blan vini rivé
 Ti bab wouj, bèl figi woz
 Mont sou koté, bel chivé
 Malè mwen, li ki lakoz
 Malè mwen, li ki lakoz
 Li trouvé choukoun joli

Stigmatism torments the individual affected by MCI. Fear paralyzes the individual similar to the pain felt by the individual to hear such news. Like in the poem/song, the participants voiced trepidations about being labeled or categorized with an illness. The *stigmatizing* of illness is debilitating not only to the individual but also to the society in which they are living.

It is uncommon for Haitians to discuss mental health issues with other people since most Haitians view mental illness as a form of punishment (Cianelli et al., 2013). Initially, **Pierre-Jacques** refused to participate in the study because he thought participating in the study would mean his PCP would be aware that he is having memory problems. The researcher reiterated that his confidentiality would be protected, so he agreed to participate. He stated:

Well I thought about it, so I decided to help you even though participating is not going to help me. I know now it is not going to hurt me too. I only came to see my doctor; what if this interferes with my doctor's appointment? I don't need him to test me until I am ready because I have to be able to take care of my wife who already has this memory thing."

He felt the stigma of the diagnosis of any cognitive problem could adversely affect his position in his world.

Marie explained that her adult children are busy with their own lives, and she is afraid of being a burden to them. She was apprehensive about a possible diagnosis because she said:

My child, here (United States) when you cannot help yourself anymore, you go to a nursing home. You cannot blame the kids. It is their time to live their lives.

I don't want to end up in a nursing home like a crazy person. I want to see if you can help me with this. I am afraid of telling the doctor but he asks me all of the times. [She laughs]. I say no I am fine. Having Alzheimer is a hard thing, but I don't think that is what is happening with me. I think I am getting old.

Having been a nursing assistant for several years, **Roberto** is aware of the effects of dementia on the individual; **Roberto** had personal experiences with the stigma of mental illness and dementia, stating:

My gosh, I don't want this awful disease. You don't see anyone in the family anymore. They just leave the affected person there (nursing home). Who can blame them? The person cannot remember anyone and you have to feed them. They do their business on themselves. I would have to move if I get this thing. Can you image the shame? I wish to find help for my wife. She does not have this Alzheimer's thing though. She has psychiatric issues. She sees her doctor all of the time, but no one knows about.

The experienced stigma, perceived stigma, and self-stigma of some of the participants regarding Alzheimer's disease make them characterize any memory issues with the worst-case scenario of dementia, which leads to uncertainty of what is occurring with themselves and with their family members. Link and Phelan (2001) indicated that *stigmatizing* is viewed as a co-occurrence labeling stereotyping separation and discrimination. There is a hierarchy of power associated with stigmatization. The stigmatizing becomes a persistent predicament in the person affected, and *stigmatizing* involves every aspect of the individual's existence from health and life itself. **Iranne** stated, "When someone cannot remember, they are crazy. That's what they called it is

Haiti.” **Bernadette** speaking regarding the protagonist of the vignette stated, “Lorencia has Alzheimer.” Her statement demonstrated that she was also stigmatizing others without knowing the facts of the illness. **Bernadette** used inferences from her lived experiences to make her conclusion.

Several participants either stigmatized Lorencia (the protagonist from the Vignette) and diagnosed her immediately with dementia. **Ginette** stated, “Lorencia would be considered distracted or absent in the head in Haiti.” **Tata** expressed concerns that others will not understand and might label her crazy. **Tata** stated “My child, they don’t know it is this cleaning blood thing that is making me that way; they might think, you know, I’m crazy. I won’t tell anyone. I stay home most of the times.” **Calvin** stated, “Lorencia doesn’t need to do the diagnostic test; she is going crazy...”

Val automatically diagnosed Lorencia with dementia because he said, “I know those kind of things; she has dementia. I exercise every day, I do puzzles, every day, I go to church, I eat right so that I don’t get this thing. My memory is going.”

Christiane’s stated, “Nurse, I can talk to you all day, who knows, I might not be able to do that later.” **Christiane** was referring to the possibility that if he develops dementia, he might not be able to communicate effectively. The attribution danger of *stigmatizing* leads to the perceived belief that the affected individual is “less than, or tainted, or discounted” from the whole of society (Brohan et al., 2010, p. 81). In a study by Brohan et al., (2010) *stigmatizing* was reported to be possibly perceived, experienced, or self-stigma.

Fearing.

The Alzheimer's Association (2011) reported that undertaking the diagnostic process early could allow better reversal of causes of mild cognitive impairment, yet "as many as half of the people with dementia have never received a diagnosis" (p. 1). The reason for the lack of diagnosis is the lack of reporting of symptoms by the affected individual due to fear of the diagnosis of dementia. Fear causes the majority of people affected MCI from seeking treatment (AA, 2011). It is reported that Alzheimer's disease is the second most feared disease in America second only to cancer (AA, 2011). *Fearing* is associated with anxiety; it could be a misperception of danger (Mendes da Mata, 2014). The *fearing* is natural and real and demonstrates the need for nursing and health care interventions.

Several of the participants verbalized not discussing their memory issues with the primary care provider (PCP) in the fear of being diagnosed with a label that is not acceptable in their environment. *Fearing* prevented certain health seeking behaviors. Henry et al. (2009) elucidated how many factors in a human situation could hinder the person's ability to function normally. At times, fear causes the person to behave in irrational behaviors or irrational thoughts. Fearful acts such as attacks, explosions, and mutilations could situational threaten in the individuals where they can no longer function to their maximal potentials (Henry et al., 2009). **Tet** feared that having a memory problem could arise similar stigmatization as he experienced when he was young. **Fente** verbalized his fear regarding possible loss of his independence and control.

Fente stated:

...For example, I always make a list when I am going to the market. I use a calendar at home. No one will know I have anything wrong with my memory until I get so bad that I can't handle it anymore, but the time this happens I probably won't care what people think. I think so.

Pierre-Jacques feared possible loss of medical insurance coverage if his wife were to be diagnosed. He feared the possible loss of his independence and identity. He currently drives and is very functional. He feared the fate of his wife if he is diagnosed, asking, "What would happen to my wife?" **Pierre-Jacques** was making arrangements for the near future, "just in case my memory start to go, my wife and I can be taken care of." Fear of the unknown was the driving factor for **Pierre-Jacques** and many of the participants' concerns with the memory issues.

Marie stated, "I know have something, but if I tell my kids, they might want me to move in with them." She feared losing her independence or becoming a burden to her children. **Marie** feared losing control if she has dementia she stated she wanted "... to know how to deal with this (tèt pa la)." **Marie** prayed every day for divine intervention. **Marie** was very apprehensive about a possible diagnosis of MCI or dementia. She felt her friend and family would treat me differently. "What if my kids want me to live with them or they take my house away? When you have this kind of disease, they think you are crazy?"

Jean expressed anger at the possibility of MCI, stating: "Haitians man..., they call you names. They jump to conclusion with everything you have..." He went on to say that "... Here (United States) you can get sick and it is normal, why then? In Haiti, every time someone is sick they jump to conclusion, and they say someone is doing it? No one in

Haiti ever dies of natural causes.” **Jean** said this with anger. Among some Haitians, illnesses are caused by supernatural causes; however, in the USA, the biomedical model of health is used not superstition as in Haiti.

Several participants either stigmatized Lorencia (the protagonist from the Vignette) and diagnosed her immediately with dementia or they feared that they were getting dementia because of the MCI.

Ginette feared a possible diagnosis of dementia even when she stated, “Lorencia would be considered distracted or absence in the head in Haiti.” **Tata** feared that her renal problems are causing her to be absent minded, but she feared that others will not understand and might label her crazy. She feared that assessment from others, saying, “My child they don’t know it is this cleaning blood thing that is making me that way, they might think, you know, I’m crazy. I won’t tell anyone. I stay home most of the time.”

Calvin feared the possible diagnosis of MCI; he kept on saying “you would sit and think, and the memory would come back.” He did not admit that he did any “sitting and thinking.” It appeared that **Val** transferred his fears about his own predicament into Lorencia’s problems.

Val automatically diagnosed Lorencia with dementia, saying: “I know those kind of things; she has dementia. I exercise every day, I do puzzles, every day, I go to church, I eat right so that I don’t get this thing. My memory is going.” Val seemed to almost state a disclaimer that he was fine but Lorencia was not; this was happening out of fear of the unknown.

Roberto feared discussing his wife mental illness with her family since he feared they will label her wrongly and stigmatize her, “I don’t even tell her family” he said. **Pierre** feared being ridiculed by others, saying, “they make fun of you when you have a mental or memory problem.” **Pierre** was fearful of becoming debilitated with any illness, saying, “When you are handicap in Haiti, they make fun of you; these kind of things don’t happen in the United States.”

Chrisiane’s memory has been failing more and more since his car accident, which caused a traumatic brain injury, many years ago. **Chrisiane** loved to dialogue, he feared he might not be able to converse well later if he develops Alzheimer’s disease so he communicated openly and freely about anything. He said, “Nurse, I can talk to you all day, who knows, I might not be able to do that later.”

Based on the premises of the RUIT, *stigmatizing* and *fearing* are also viewed as antecedents of uncertainty. In connection with the RUIT, Mishel (2010) explained that anything that affect the patient’s thinking such as pain, prior experinces, and perception are antecedents of the uncertainty. *Stigmatizing - fearing* are placed in the Structure Providers Frame since ideally this frame is used to provide resources to the individual who is affected. The resources are unique to each individual affected. The individual’s education, social support, and credible authorities are located in that frame. The people in this frame are the people whom the affected individual would trust and confide; credible authorities are usually health care providers. Unfortunately, due to the nature of the syndrome and the ability of the individual to function normally, they typically do not use the resources and even hide from the resources. Some of the particiapnts in this inuqiry were relying uniquely on lived experiences as their sole sources of information

regarding MCI. Mishel (2010) explained that education and social support allow the person affected to gain knowledge about the illness event. Denenny, Bently, and Schiffman (2014) explained that the public's perception on the association of schizophrenia and violence is exaggerated; however, there is a biased portrait of stigma that exists regarding the association. The authors aimed to report the validity property of a test to capture the implicit perception of people with schizophrenia. The authors reported that stigma towards people with schizophrenia has lead to serious and at times deadly consequences such as social exclusion, untreated illness, and suicides (Denenny et al., 2014). *Stigmatizing* exists in all fields of the health care system including and is not limited to MCI or mental health.

Benbow and Jolley (2012) documented that the stigma distorts services in all levels of the person's interaction. The reduction of stigmatism is beneficial for all people from the patient to their social interaction with friends and family. The reduction of stigmatism is also beneficial in education/information, research and through healthcare policy making decisions. The authors argue that labeling patients with dementia as crazy is not only fundamentally wrong but includes negative stereotyping, prejudice, and discrimination (Benbow & Jolley, 2012). Boise, Camicioli, Morgan, Rose, & Congleton (1999) explained that the subtlety of dementia makes difficult to recognize changes in cognition from a single PCP visit. Within their study, 16 of the 18 participants were brought in by their families who first recognized the changes in cognition. The PCP promptly took actions to identify the causes of the impairments. Limited time, lack of routine screening, and patient-PCP interaction were among the reason some of the syndromes and symptoms were missed by the PCP. Nevertheless, the affected

individuals in their study did not report their symptoms to their PCP due a number of reasons including but not limited to stigma and fear.

Fear was recognized as an important factor in people with MCI and dementia. The authors emphasized that threat process is an important attribute in cognitive impairment since the individual can properly assess danger. Although, to a lesser extent, Henry et al. (2009) reported that the individuals affected with MCI could perceive the treat perception of illness similarly as those affected with dementia. The purpose of their study was to evaluate threat perception in individuals with MCI, dementia, and normal aging. The detection of threat was associated with emotion processing. The participants' perception on threat recognition was precise; the authors concluded that all three groups were able to accurately differentiate the threat proceses in situations presented, although the dementia group had difficulties recognizing the level of threat as being high to low danger.

Doubting

The study participants appraised MCI syndrome as doubtful event. *Doubting* is viewed as an appraisal of uncertainty in relation to the RUIT. The uncertainty in illness at times begins with a fluctuation from the norm. Mishel (1990) explained that in qualitative investigation of uncertainty, if the person lives with the uncertainty for a long time, he or she eventually views the experience of uncertainty as a positive concept. This implication means the appraisal of uncertainty evolves over time. *Doubting* is neither a positive nor a negative concept at the appraisal phase. In this inquiry, the doubts raised questions about whether the disease process of dementia as begun. It was hoped by most of the participants that based on their prior experiences with the devastating illness of

dementia that such processes has not begun within themselves or within family members. The participants were mostly positive and hopeful about having a lack of pathology association with the MCI or most notably dementia. They denied having signs of memory problems even when they described symptoms of their own memory problems. As in the song *Memory*, some of the participants at times doubted and blamed their own memories for deceiving them. The song “*Memory*” from *Cats*, the Broadway musical, recapitulates the feelings of doubt and hope of the participants. The memory becomes deceitful; it takes a life of its own. Memory becomes its own entity, and it becomes a force to cogitate. The memory causes such disillusion in uncertainty. The irony of the memory is reflected in the song. The song is reflective of the data collected especially concerning *doubting* of any event during the lived experience of the participants.

“Memory”

Midnight

Not a sound from the pavement
Has the moon lost her memory?
She is smiling alone
In the lamplight
The withered leaves collect at my feet
And the wind begins to moan

Memory

All alone in the moonlight
I can smile at the old days
I was beautiful then
I remember
The time I knew what happiness was
Let the memory live again

Every street lamp

Seems to beat a fatalistic warning
Someone mutters at the street lamp gutters
And soon it will be morning

Daylight

I must wait for the sunrise
 I must think of a new life
 And I mustn't give in
 When the dawn comes
 Tonight will be a memory too
 And a new day will begin

Burnt out ends of smokey days
 The stale cold smell of morning
 A street lamp dies, another night is over
 Another day is dawning

Touch me
 It's so easy to leave me
 All alone with my memory
 Of my days in the sun
 If you touch me
 You'll understand what happiness is
 Look a new day has begun (Song Lyrics, 2016).

In relationship to the RUIT, *doubting* is viewed as an appraisal of uncertainty where the person is placing value on the uncertainty of the situation (Mishel, 2010). Some of the participants viewed MCI as an opportunity to improve their health status; for example, **Val** and **Pierre** discussed their exercise routines; some participants, such as **Marie**, **Rose**, and **Iranne**, viewed MCI as a treat to their independence and daily lives. Still other participants like **Alourdes** and **Calvin** were not informed enough to make an accurate opinion of their situation. Some participants make inferences of the uncertainty based on their lifeworlds. *Doubting* involves uncertainty of all aspects of the lived experiences of the person. Being unsure of the experience brings feelings of doubt. Then, in-doubt people develop a mistrust of themselves, and it affects their self-esteem and well-being. Phinney (1998) wrote that gaps of unawareness occur when the person does not recognize the symptoms and he or she becomes forgetful and disoriented. Some of the participants were aware that certain changes were occurring, but they used wishful

thinking to deny the process. Other participants used supplementary measures to deal with the changes. **Val** affirmed that he was making a lot of effort to avoid the worst of a memory disorder. As identified by Phinney (1998), **Val** tried to be normal – “I pray the rosary every day because it is something that I do all of the time. I don’t go to places that I don’t know; that’s the way I function well.” Keeping their activities routine helped the participants to cope with the forgetfulness.

Calvin, speaking about the vignette, said, “What’s the use of testing, if it is something bad, it has already happened anyways?” **Calvin** doubted that anything positive could be done to improve the memory once the cognitive decline has started; he felt once the process has started, it becomes a matter of resignation and defeat. **Rose** doubted there is anything wrong with her memory; she attributed the memory problem to her recent surgery and her “thinking too much.” **Rose** said, “Well this cannot be anything bad because I am able to take care of my grandchildren every day. I take care of the house too. I don’t think this is anything bad. It is just old age.” **Grace**’s son died; she was sure it was related to supernatural causes, and she felt “it is thinking too much that is making me like that (forgetful).” She doubted her forgetfulness was a medical problem. **Grace** was viewing the MCI from her cultural perspective. Cultural background, life experiences, and age contribute to the belief system of the individual (Nudelman & Shiloh, 2011).

Causal attribution of memory problem was more positive when the participant felt the memory problem was a norm for any aging person. Many participants talked about acting normal, staying occupied with tasks, keeping the mind active with music, with prayers, reading and exercising. Most of the participants modulated their concerns about

the etiology of the memory problem. However, as indicated by Phinney (1998), most of the participants struggled to understand the experience. Although Phinney's research came out in 1998, the article was used because it is very relevant to this study; it directly connects to the theme and to the perception of individual affected by dementia. **Iranne** doubted that anything is wrong with her memory, but she struggled to remember her activities from yesterday. **Iranne** denied having MCI but communicated she experiences a lot of forgetfulness all of the time, so she was hoping the researcher could explain her experiences. *Doubting* caused **Iranne** to seek some help to understand her symptoms.

Scarlene had a heart attack and a stroke; she confessed that her blood sugars are not well-controlled, but she doubted the possibility of any cognitive impairment. She said, "I am fine; I just can't remember because I have a lot on my mind." **Jean** talked about the supernatural beliefs of other people, which he believed cause people to forget. He has diabetes and had a heart attack; he was worried that his chronic problems could make him more forgetful, but he was not sure since he has not discussed the problem with his health care provider. **Jean** stated, "At times, I wonder if all of these medications and this diabetes are making me forget things. When you see the doctor, you handle important business not this issue of forgetting, people are supposed to forget, don't you forget?" This questioning was a common phenomenon where a few of the participants asked if other people have similar circumstances of forgetfulness. The participants wanted to feel that they are not alone and that memory problems are typical of many people. **Jean** continued "I don't think anything is wrong with me; other people have this (MCI) too."

Ginette doubted that she could be having anything wrong with her memory. **Ginette** stated “You become a little forgetful when you get older...” She reasoned that if it had been anything else she would not have been able to take care for her grandchildren

Ginette mentioned, “Every day while their mother is at work, I take care of them (grandchildren). I would not be able to do that, if I had memory problems.” **Marie** doubted whether she had MCI. She said, “I am afraid of telling the doctor but he asks me all of the times.” [She laughs], “I say no I am fine. Having Alzheimer is a hard thing, but I don’t think that is what is happening with me. I think I am getting old.”

Alourdes doubted having a serious memory problem because as she stated, “I cannot have a memory problem because I can take care of the kids and the house.”

Roberto doubted and denied a possible serious memory problem based on his age, stating: “I am not old enough. I work with people with Alzheimer's disease that's not how they are. They don't remember their families; we have to help them with everything. What I have is not the same... .”

Chrisiane was having marital problems, and then he started *doubting* whether he was having a cognitive issue or whether the memory issues were only situational. He said:

I was tested. I don’t remember the number but they said I have ... I am good for now. The accident left me paralyzed, and my family did not help in that sense. I think they (his family) might be making my memory worst.

Chrisiane explained that his car accident many years ago left him physically disabled. He was able to adapt to the disability. **Chrisiane**’s major problem is the decline of his memory. Even though he was officially tested for MCI, he still felt his family is one of

the aggravating factors of his MCI. He doubted his family's commitment to his well-being. He doubted the test results. **Pierre** doubted that anything could be done to either slow the progression of any cognitive disorder; he doubted any treatment plan would work. **Pierre** stated:

In Haiti, when someone has memory problem that say the person is crazy, I don't think that is true. Here, I think they have medications that can treat the problem, why don't they treat this problem already. Maybe, they don't even understand it. It's like my glaucoma. They could do something about my glaucoma but no, they keep on giving me eye drops. I don't think they will do anything about my memory problem, but I am better off here than in Haiti.

Antoine doubted having "anything serious." **Antoine** volunteered to participate in the study but denied having MCI; he said "oh, I just forget a thing or two sometimes." He stated, "I have a little bit of a problem with my memory." Antoine seems to be in denial because he went on to explain that he is losing business because he cannot remember his appointment. He said:

I would get home and I remember, oh my God, I told this lady I would pick up her boxes since this morning. Sometimes the clients would get mad at me. But it is not my fault. I am just so busy. Madame, sometimes I just don't remember the clients. I really think I am just over-worked and there is nothing wrong my memory. After all, I am working, I am taking care of my bills.

During the interview, he appeared to be searching and rationalizing his thoughts. It appeared **Antoine** was not convinced of this statement and appeared unsure of himself; he was shy and introverted.

Tet explained that his traumatic childhood could have caused him to have memory problems today. He said:

I am not sure but I think being teased for stuttering as a young person could have created some mental defects in me, I think it is all related. Music helps me to cope but the torment I suffered as a child I think created a lifelong complex in me.

Tet was constantly doubting the events his life as contributing factors for his forgetfulness.

Fente felt all people suffer from memory problems, but their education helps them to cope and to think. He verbalized:

If you are cultivated, then you will be just fine; you can find ways to hide your forgetfulness; if you are not educated you cannot hide it. I don't think anybody is normal. We all have the same memory problems; everybody forgets in their old age; it is a scientific fact.

Fente was in doubt about the MCI but he felt better by attributing his coping to his education level. She felt that if someone is educated, then it is likely that he or she will not experience MCI or any memory problems. **Fente** exclaimed, "I am cultivated; those kinds of things don't really happen to people who are cultivated."

According to Howard (2014), a lack of knowing causes anxiety, and the anxiety causes self-doubt. To resolve the *doubting* that exists, the person needs to make an assessment of the information or of the phenomenon; therefore, the person will be able to make necessary adjustments in thinking. Mast (2009) explained although dementia does not trigger depression, it does alter the thinking process and the future of the individual. The uncertainty may affect the lifeworlds (self, time, and relationships) of the individual.

The individuals might live in the “here and now” or live in the past when they have dementia (Mast, 2009). The anxiety of possibly having a dementia diagnosis causes unreasonable doubt at times. The participants had a more positive experience when they believed the memory was attributed to a cause such as a car accident, recent hospitalization, or surgery and anesthesia. Attribution of the disease varies among people and their cultural background and their experiences (Nudelman & Shiloh, 2011). Nudelman and Shiloh (2011) studied 200 research subjects about the relationship between their beliefs about justice, illness causal attributions and fairness judgment of those causes. Questionnaires were used. The results revealed that the individual’s judgment of fairness and causality of illness is influenced by his or her perception of the attribution of the illness. These causes could be hidden causes such as mystical, genetic, or psychological, or they can be environmental causes. The authors indicated that the perception of the individuals based on the causes of their illness could resort to anxiety and anger or could induce positive or helping behaviors. With qualitative research, particularly phenomenology, there is no right or wrong belief. There is a question of how the phenomenon is perceived by the individual.

Many research studies use Merle Mishel’s (2010) Reconceptualized Uncertainty in Illness Theory (RUIT) to evaluate uncertainty in illness by using the Mishel’s Uncertainty in Illness Scale (MUIS). The RUIT provided a foundation for the researcher to comprehend the theme of *doubting*. In this inquiry, *doubting* was considered to be the end product of the appraisal of uncertainty based on the information provided by most of the participants. Most of the participants viewed MCI as a threat—a danger—and they formulated plans to rectify the anomaly of their memories. Based on the data collected

and the knowledge base of most of the participants, this researcher concluded that the formulation of any plan to remedy the problem of MCI cannot be successful without the participants' possession of proper information regarding MCI. During the uncertainty, some assumptions must be met to resolve the uncertainty. One assumption is ambiguity or *doubting* concerning MCI; the ambiguity must be addressed. The individual needs to understand the complexity of the illness and its treatment options. Based on their prior experiences, most of the participants witnessed dementia and mental illness at the end stage, which is usually petrifying; therefore, naturally, the participants thought of the worst-case scenarios for themselves. Another assumption to be addressed is the lack of information about MCI and its seriousness; the unpredictability for the course of the illness and its prognosis produces significant anxiety. The cognitive process of the individual is mildly affected, coupled with some cultural incongruency, which created a feeling of double jeopardy of *doubt* for the participants (Adamson, 2001; Nicolas, DeSilva, & Grey, Gonzalez-Eastep, 2006; World Health Organization [WHO], 2010).

Spiritualizing – Praying

The cosmocentric culture of Haiti causes Haitians to understand certain health issues differently than the rest of the Western world. For example, in Haiti, health is considered to have a connection with the environment. The state of “being-ill-with” results from a loss of harmony between the components of the person and/or between the person and one or more elements of the environment (WHO, 2010).

The World Health Organization (2010) reported the following about Haiti:

- The indicator of health and well-being is the experience of harmonious integration in the environment.

- Classification of illness: Illness is not only physical, mental, or psychosomatic.
- It is a non-observance of the rules that govern the human relationship with the physical environment. Illness includes:
 - Non-observance of rules of hygiene
 - Non-observance of ethical rules
 - Malign influence of others (poisoning, sorcery)
 - Non-respect of the rites or prescriptions
 - Regarding the ancestors and/or spirits
 - Manifestations of hereditary or genetic problem
 - The origins of Illness include:
 - Non-observance of rules of hygiene (nutrition, toxins, microbes, etc.)
 - Pathogenic interpersonal factors (poor emotional care, loss, trauma, etc.)
 - Psychosocial stress
 - The Classification of Illness is: Maladi Bondyè means domain of visible or “ordinary” physical illnesses; The illness can be healed with the aid of Western medicine or a doktè-fèy (traditional healer). Maladi fè-moun mal (or maladi diab) means domain of the invisible, secret or magic. The illness can be healed by intervention of a bòkò or a traditional oungan practitioner. Maladi lwa means domain of the invisible spiritual; the illness can be healed by an oungan practitioner.
- The Mode of Healing Intervention: Divination of the nature and meaning of malaise. It includes:
 - Mediation with the universe of spirits

- Prescription of measures include rituals
- Realignment of energies
- Active participation of patient (search for plants, pilgrimage, dance, etc.).
Mobilization of social networks and knowledge networks.
- Links with the moral, social, and political
- Participation of the client in remuneration of the healing (financial or otherwise)
(pp. 9-10)

As demonstrated by the complexity of the information listed above from the WHO (2010), and as previously communicated by numerous researchers and scholars (Colin, 2009; Desir, 2015; Desrosiers & St. Fleurose, 2002; Nicolas et al., 2006), *praying* and *spirituality* are culturally significant to Haitians. Desrosiers and St. Fleurose (2002) eloquently warned in their report:

To provide competent care, the non-Haitian professionals need to be knowledgeable in the culture practices aspect of Haitians because as a group, Haitians with mental illness have been perceived to be a challenging group to treat since their views and concepts of the world are unique. Among others, adversities such as economic factors and political stresses also influence the worldview of Haitians. The historical perspectives of Haitians shape their society, the family, and the individual. The voodoo beliefs and practices shape attitude and compliance responses to the treatment plan. These concepts are imperative for the health care worker and nurses to comprehend to reduce and manage treatment failure (p.509).

Religious practices, including unstated voodoo practices, highly influence the Haitian psyche (Colin, 2009; Desrosiers & St. Fleurose, 2002). Cultural beliefs of voodoo are deeply rooted into the psyche of the participants to the point that they make causal reference to voodoo affecting their health as easily as a Westerner would comment on the effects of cigarette smoking or the use nicotine on their health status.

The Haitian health belief system is rooted in spirituality. According to Evans (2016):

Historically, Vodou has been the essence of the Haitian people; that is, it constitutes our identity, our “self.” It is through the lens of Vodou that most Haitians view and understand the world around them. It is through this frame that socio-political, environment, spiritual, economic, and health construct are assigned, therefore, one cannot overlook Vodou in consideration of Haitian well-being. (p. 7)

An illness in the Haitian culture constitutes an imbalance. In the Haitian culture, the etiology of illness could be attributed to many factors including supernatural, curses, offending of the Lwa (deities), naturally induced, or as a strained relationship between the God-person relationship (Nicolas et al., 2006). Voodoo is a widespread practice of most Haitians, although most Haitians identify themselves as Catholic. Haitians are aware of cultural beliefs in magic and spirits; some choose to reject them, some embrace them, and still others are in the middle. The belief and practice of voodoo differs based on the region of Haiti. Voodoo is not only a religion, but it constitutes a health care system that includes healing practices, health promotion and prevention of illness, and promotion of personal well-being (WHO, 2010, p. 7). Some Haitians believe that angry

spirits could cause illnesses, they believe if someone has an illness, that person must be isolated because if the person makes contact with other individuals, the contact could make the other individuals ill (Cianelli et al., 2013).

Historically, a general hostility exists in the relationship between mental health providers and religious/spiritual leaders (Alexandre, 2016). The hostility stems from the philosophical and metaphysical ideas about religion and spirituality. Religious leaders are typically suspicious of spiritual leaders. The fundamental problem is that mental health practitioners usually do not value certain religious practices, while religious leaders, at times, do not see the need for psychological intervention since it is believed all problems can be resolved through prayers, confessions, and repentance (Alexandre, 2016). Alexandre (2016) argued, consequently, that “serious mental health needs may be overlooked, appropriate referral may be delayed and appropriate treatment methods such as the use of medications to deal with certain mental disorders, may be discouraged” (p. 9). Spirituality and religion are helpful to the participants; they help the participants to deal with many stressors of life including but not limited to natural disasters, illness, loss of loved ones, divorce, and serious mental illness.

Val worried about the increase in absentmindedness that he is experiencing. **Val** stated he prayed, he did jigsaw puzzles, and he recited the Holy Rosary daily to keep his brain active. He performed physical activities and weight training exercises regularly. He said, “I am afraid of what might come, but I trust in God that I will remain healthy.” **Val** prayed as a way to remain healthy physically and mentally while he is experiencing lapses in his memory.

Pierre attended religious services on Saturdays since he is a Jehovah's Witness. He said, "Oh of course, I go to temple regularly." **Gerard** stated, "after God is doctors." **Gerard** was a man of few words but proclaimed his love for God, stating "...yeah I pray regularly." **Pierre-Jacques** said "... my wife is sick so I don't go to church all of the times but I go to church once a month ... the first Sunday of the month to receive communion." Finally, **Fente** nonchalantly mentioned, "I attend church all of the time."

The majority of the participants cited praying as a regular ritual they performed routinely. **Tata** prayed that she might be able to return to Haiti to see the rest of her family; "I pray that I can go home one day before I die" **Roberto** mentioned he was Baptist. **Roberto** worried about the fate of his wife, and he stated, "I pray that she can find some help with her memory problems. She is so young. We have a small child." **Marie** exclaimed that she practically lived at the church. "I pray for other people and for myself. You know prayer is like a meditation; I always feel good when I go to church." **Tet** played the organ in his Baptist Church. **He** stated, "I find solace in playing music. Music helps me to cope with everything. I play mostly for the church. I play in other places too; playing music calms me down; I think clearly when I play." **Alourdes** announced that she prayed daily, and the church provides her an occasion for socialization. She stated, "They (fellow church members) give me a ride to the church and to prayer meetings, I don't drive." **Antoine** worried about forgetting important work-related appointments, which could affect his compensation, so he stated, "I pray a lot."

The next paragraph is intended to demonstrate an association between health and well-being and the spiritual beliefs of the participants. Some of the participants requested

divine interventions in whatever daily endeavors regardless of etiology. At times, the divine intervention is in reference to supernatural forces. None of the participants attributed memory problems or MCI to supernatural causes because they viewed MCI as problem of Western origin. Several participants nonchalantly mentioned voodoo passively. **Etienne** said, “I know who killed my son, but I am a man of God.” He continued to explain that he will not revenge of his son since he is “a man of God.” **Etienne** was nonverbally saying he would not seek revenge for the death of his son because he was strictly practicing Christianity. Being suspicious of the purpose of the research, **Iranne** was apprehensive and reluctant to speak to the researcher; she finally was at ease to speak after the researcher re-emphasized to her that she did not have to answer any questions that she was uncomfortable with. **Iranne** shared of her *praying* for her “friend to get healed.” **Iranne** described that she had a dream; she dreamed that she healed the person via a vision. She said:

I was just sleeping and someone said, come do something for this person, do you know? I took her to the church, I had another vision in the church and she is healed. She still calls me until today to say thank you, she moved to another town now.

Iranne continued to say during the interview, “they cannot do anything to me, when you are serving God, Satan cannot touch you.” She spoke of supernatural dreams and her dreams of Jesus as her protector and her light. Voodoo is considered to be a way of life for most Haitians whereas even **Iranne**’s Christian belief could not hinder her from believing that she healed her friend. **Iranne**’s belief was also confirmed by Byrne (2010) who stated through the law of attraction, all human beings have the power within

themselves to do whatever they wish, positively or negatively. **Grace** stated, “I know who killed my son but I am a Christian, so I cannot get involved.” This statement confirms the words of Beaubrun (2010), who stated: “Vodou existed before the ceremony of Bwa Kayiman, Vodou is the Spirit, the Mystery, the Invisible, the Unknowable. It is all about a philosophy of life. One has to experience it to know it” (as cited in Evans, 2016, p. 9).

As previously mentioned by the WHO (2010) report, the classification of an illness is an important factor in the Haitian health belief system. **Scarlene** did not elaborate on her suspicions, but she could have perceived that her illness to be classified in any of the categories below. The illness could be, Maladi Bondyè: domain of visible or “ordinary” physical illnesses; this type can be healed with the aid of Western medicine or a doktè-fèy (traditional healer). The illness could also be Maladi fè-moun mal (or maladi diab): domain of the invisible, secret or magic. **Scarlene** mentioned that she is young and finds it hard to believe that she could suffer from heart disease. She is suspicious about the nature of her illness, but she did not make any inferences. **Jean** mentioned that he was angry regarding the practice of voodoo in Haiti and expressed:

because people jump to conclusion in Haiti, no one ever dies of natural causes in Haiti. Someone is always causing someone harm, it is not true, how come it is not like that here (United States)? Here people die of strokes, heart attacks, car accident, and other things. Right, nurse?

It is imperative to understand the personal struggles occurring within the individual who is crossed between two different cultures. There are some conflicts regarding health belief in Haiti and that of the Western worlds. Health care providers

need to encourage the individual to share their cultural beliefs and practices to provide better care. Often, the practitioner's biases interfere with the treatment plan or intervention for the individual, especially when the practitioner asserts his or her health belief as the only valid health system belief in existence. This researcher believes that **Jean** was trying to comprehend the two health systems. Alexandre (2016) cautioned:

For more than 500 years, Vodou has been and remains an organized system rooted in the social and cultural practices of the Haitian Society. It provides its devotees and supporters with methods of prevention and treatment of the mentally ill based on a specific framework. (p. 21)

Thus, it is expected for the participants to struggle with whatever illness or uncertainty they are facing, and it is natural and normal for them to attempt to make sense of it the best way they know.

The nurse is in a unique position to help the patient and his or her family to address problems related to their health care and cultural diversity most notably MCI is addressed in this inquiry (NIH, 2016). As stated by Wright (2005b), spirituality is not new to the nursing profession since even Florence Nightingale called for the spiritual focus of nursing practice. "Nightingale believed that she was called by God to serve humanity, to contribute to the development of a sense of spiritual well-being in the patients" (Wright, 2005a, p. 65). Many of the articles reviewed specified that, at times, nurses' focus more on the physical aspect of illness instead of the spiritual well-being of the individual (Nicolas et al., 2006; Wright, 2005b). Ethnic minority populations should feel empowered to actively interact with the health care workers without excluding the expression of spiritual beliefs.

As depicted in the demographic data, 12 of the participants identified themselves as Catholic, eight were Baptist, and one was a Jehovah's Witness; one hundred percent of the participants associated themselves with some form of spiritual movement. Faith dictates the health promotion choice and well-being. Faith and spirituality is intertwined with hope. Religion inspires the feelings of hope. Hope during illness is considered to be a process and resource for adaptation (Cotter, 2009). Hope is viewed as inseparable with faith. Cotter (2009) wrote, "The enduring quality of hope provides an affirming testimony to the human spirit and can form the bridge that links our common humanity to persons with Alzheimer's disease" (p. 298). Hope is viewed as a catalyst to assist the individual to cope with changes in life and to function adequately with chronic illness.

The Biomedical and Holistic Models of health care are interfaced in this inquiry; the importance of spirituality regarding health, illness, healing, and hope was very strong among the participants of this inquiry. Prayers were the primary alleviating factor among the participants. In this study, the participants were trying to accept the uncertainty as a part of their daily life. Acceptance and adaptation were exhibited through prayers and spirituality (see Figure 8).

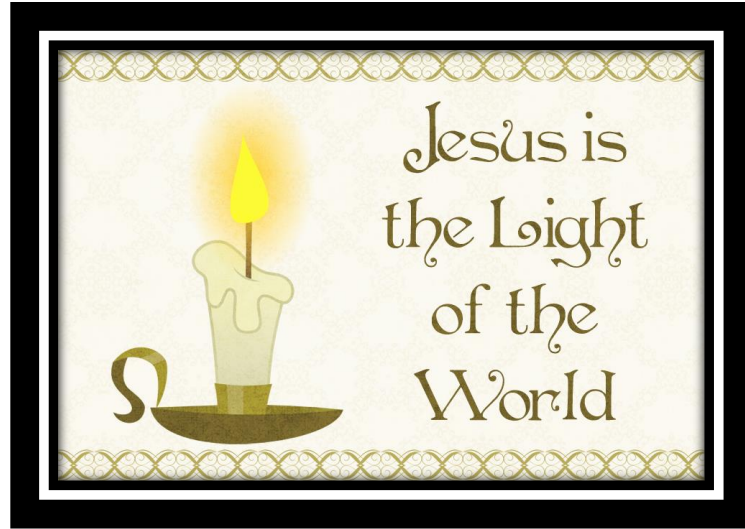


Figure 8. Jesus is the light of the world: John 8:12.

Praying

Religion can create a sense of coherence, meaning, and stability (Alexandre, 2016). People with chronic illness draw on faith and use spiritual practices such as prayers to make sense of their suffering and/or to be able to manage their health (Unantenne, Warren, Canaway, & Manderson, 2013). Most Christians recognize their limitations and recognize that they need God who is more powerful to govern and intervene in their daily lives; therefore, they pray for intercession and mercy. Most Haitians view personal and mental health problems as either a family or a religious matter, so they are more likely to turn to spiritual leaders before they go to a mental health practitioner. *Spiritualizing* and *praying* are incorporated into self-management of the uncertainty of the illnesses since *praying* has a positive impact on the individual's health and well-being. There is a positive relationship between religion, spirituality, and health. Attending a structured religious ceremony is as important as visiting the health care provider for some of the participants. **Grace** said, "When I pray, it helps me to remember." She continued, "God has done so much for me." She prays for strength in

her day-to-day struggles. She believes that someone killed her son with supernatural elements. **Rose** added: "... I go in my room and I enter in communion with my Savior (God), He always takes care of me." **Rose** felt her memory problems are due only to the surgery she had 6 months ago, and she stated "... I pray to God to take it away." At another point, **Rose** said, "with the grace of God. I will be fine."

Ginette stated: "I pray so that I can remember. I get very angry or little angry sometimes. I get frustrated, then I pray and all is well." **Ginette**, like many other participants, believed they are themselves spiritual being and that they are connected to the universe. They believed when they live in harmony with the greater power, everything is satisfactory, including their health.

Tata, speaking of her faith, stated, "I pray that I get to go home again. You think God will let me die here (United States)? Without seeing my home again? I don't think so. I fear it might happen, though." **Tata's** concern is that her memory might worsen before she gets to go home. She feared she might forget her family in Haiti; because of all of her concerns, **Tata** prayed regularly. **Marie** said, "Praying to God helps me in everything I do, it gives me strength. Praying is my life; it is all I have. Jesus is my light."

Religion was used to reduce anxiety; it offers a sense of hope, and a sense of purpose and meaning can be derived from religion, which creates emotional well-being (Alexandre, 2016). Alexandre (2016) depicted the benefits of religion:

Religion promotes social cohesion, it offers a sense of identity, it satisfies the need for belonging, it unites people around a shared understanding, it provides a solution to situational and emotional conflicts, it resolves the problem of death

through belief in an after-life, it provides a sense of power and control through association with an omnipotent force, it encourages service to others and self, and it suppresses self-destructive practices. (p. 17-18)

Tet indicated, “When I get frustrated with it all, I pray to God, I play my music, spiritual music, you see.” **Val** mentioned, “I pray and I exercise to keep my brain active.”

Bernadette started praying for the dissertation to be successful. She belongs to the choir group at church and leads the rosary prayers. **Bernadette** felt when she keeps her daily activities routine and when she prays, her memory is more reliable; therefore, she keeps herself occupied with church activities to establish a constant norm in her life. She keeps track of her days through the church activities. **Bernadette** said, “if my friend Paula calls me to give me a ride for choir practice, then I don’t even need to check the calendar because I know today is Wednesday and things like that.” **Pierre** was sad about having glaucoma in addition to this memory issue, saying, “I used to draw, but I cannot anymore. I leave my health in the hands of God.” **Etienne** said, “I am blessed, I have many troubles but I am here, so I am blessed, I have faced so many adversities but I am here.” **Christiane** said, “God is my strength and my refuge. I pray all of the times. I don’t want to have this thing. I pray that he takes it away.” He expressed that he went to church all of the time. In most of the cases, the participants successfully achieved complex functional planning in the presence of uncertainty. Uncertainty does not debilitate the participants to the point of destruction; instead, the participants had deeply helped religious convictions that overpowered the negative factors. Byrne explained that illness does not reside in a body that has harmonious thoughts; it appears that the participants innately believed this philosophy without having learned it through formal

education (Byrne, 2006). Despite many adversities, most of the participants reflected positively on their lives. They were thinking of positive and hopeful thoughts even when they were worrying about the meaning of their MCI. Unantenne et al. (2011) explained that strategies for adaption in illness often incorporated and included *spiritualizing-praying*. *Spiritualizing – praying* had a positive impact on the individual health and well-being and lead to better disease management (Unantenne et al., 2011).

In connection with the RUIT, *spiritualizing* and *praying* were used as positive coping strategies, which through probabilistic thinking are viewed as opportunity for betterment. Probabilistic thinking encourages a new sense of order; the nature of the uncertainty is accepted as a natural rhythm of life. Probabilistic thinking asserts that nothing is certain and that some outcomes are unpredictable. The participants were able to properly demonstrate self-organization of their daily lives to cope with MCI or memory problems. This was exemplified when **Val** stated, “I take the same road every day so that I don’t get lost or get confused.” Additionally, **Pierre-Jacques** professed the use of a calendar to maintain order of his endeavors. The spiritual well-being of a person accounts for his or her health status because the individual is continuously growing and developing. When there is a spiritual connection to a higher power, the person thrives regardless of adversities. In the RUIT, Mishel (1990) would concur that adaptation has been achieved when the participants communicated they could cope with the uncertainty of MCI because of their praying efforts. The sentiments of the participants are reflected in the following statement:

Make everyday life your spiritual practice. When the milk boils over, when the bathroom flush doesn’t work, when your colleague steals your idea and the lady

standing next to you in the train is stepping on your toe, rejoice and give thanks.
(as cited in Wright, 2005a, p. 1).

Val worried about the increase in absentmindedness that he is experiencing. He stated he prayed, he did jigsaw puzzles, and he recited the Holy Rosary daily to keep his brain active. He performed physical activities and weight training exercises on a regular basis. “I am afraid of what might come but I trust in God that I will remain healthy.”

Val prayed as a way to remain healthy physically and mentally while he is experiencing lapses in his memory. **Scarlene** stated, “I tell you, sometimes, I feel so bad that I spend the whole day in bed, thank God my husband is nice and he helps me. I wonder if something else is not causing my memory problems, I go to church and pray all of the times for this to pass. God is good, he will help me through it (memory problem).”

Jean stated he attend church services regularly, stating “I go (to church) all of the time.” **Pierre** attended religious services on Saturdays since he is a Jehovah’s Witness; he said, “Oh of course, I go to temple regularly.” **Gerard** stated, “after God is doctors.” **Gerard** was a man of few words but proclaimed his love for God, stating “...yeah I pray regularly. **Pierre-Jacques** said “... my wife is sick so I don’t go to church all of the times but I go to church once a month ... the first Sunday of the month to receive communion.” Finally, **Fente** nonchalantly mentioned, “I attend church all of the time” and admitted praying.

The majority of the participants cited praying as a regular ritual. **Roberto**, who was Baptist, worried about the fate of his wife, saying, “I pray that she can find some help with her memory problems. She is so young. We have a small child.” **Alourdes** announced that she prayed daily and the church provides her an occasion for

socialization. She stated, “They (fellow church members) give me a ride to the church and to prayer meetings; I don’t drive.” **Antoine** worried about forgetting important work-related appointments, which could affect his compensation, so he stated, “I pray a lot.”

The poem “Still I Rise” by Maya Angelou depicts the courage, strength, and tenacity of the participants despite all adversities of life, they are still standing.

“Still I Rise”

Maya Angelou, 1928 - 2014

You may write me down in history
 With your bitter, twisted lies,
 You may trod me in the very dirt
 But still, like dust, I’ll rise.

Does my sassiness upset you?
 Why are you beset with gloom?
 ‘Cause I walk like I’ve got oil wells
 Pumping in my living room.

Just like moons and like suns,
 With the certainty of tides,
 Just like hopes springing high,
 Still I’ll rise.

Did you want to see me broken?
 Bowed head and lowered eyes?
 Shoulders falling down like teardrops,
 Weakened by my soulful cries?

Does my haughtiness offend you?
 Don’t you take it awful hard
 ‘Cause I laugh like I’ve got gold mines
 Diggin’ in my own backyard.

You may shoot me with your words,
 You may cut me with your eyes,
 You may kill me with your hatefulness,
 But still, like air, I’ll rise.

Does my sexiness upset you?

Does it come as a surprise
That I dance like I've got diamonds
At the meeting of my thighs?

Out of the huts of history's shame
I rise
Up from a past that's rooted in pain
I rise
I'm a black ocean, leaping and wide,
Welling and swelling I bear in the tide.

Leaving behind nights of terror and fear
I rise
Into a daybreak that's wondrously clear
I rise
Bringing the gifts that my ancestors gave,
I am the dream and the hope of the slave.
I rise
I rise
I rise.
(Poets.org, n.d.)

Reconceptualized Uncertainty of Illness Theory Connection to the Themes

The RUIT allowed the researcher to understand the experience of the individuals living with continual uncertainty. In this inquiry, the coping mechanism and adaptation to the uncertainty of MCI of the 21 participants was better understood through the connection to the RUIT. The aim of this inquiry was to understand and to describe the essence of the lived experiences of Haitians with MCI living in South Florida. The analysis of the themes and subthemes *blaming*, *stigmatizing - fearing*, *doubting*, and *spiritualizing - praying* and the connection to the RUIT will be discussed.

Although some of the terminology of the RUIT is different from the UIT, the theoretical model schema, the definition of uncertainty, and the major themes remain the same for both theories. Two new concepts were added to the RUIT; these concepts are self-organization and probabilistic thinking. Furthermore, while the desired outcome of

the UIT is adaptation, the desired outcome of the RUIT is growth to a new value system through the expansion of consciousness. When uncertainty is assessed as a danger, it is viewed as harmful. Then, problem-focused strategies are used to reduce the danger, or emotional coping strategies are used to respond to the uncertainty and adaptation occurs (Mishel & Clayton, 2008). Figure 9 is the UIT Model, which also represent the RUIT.

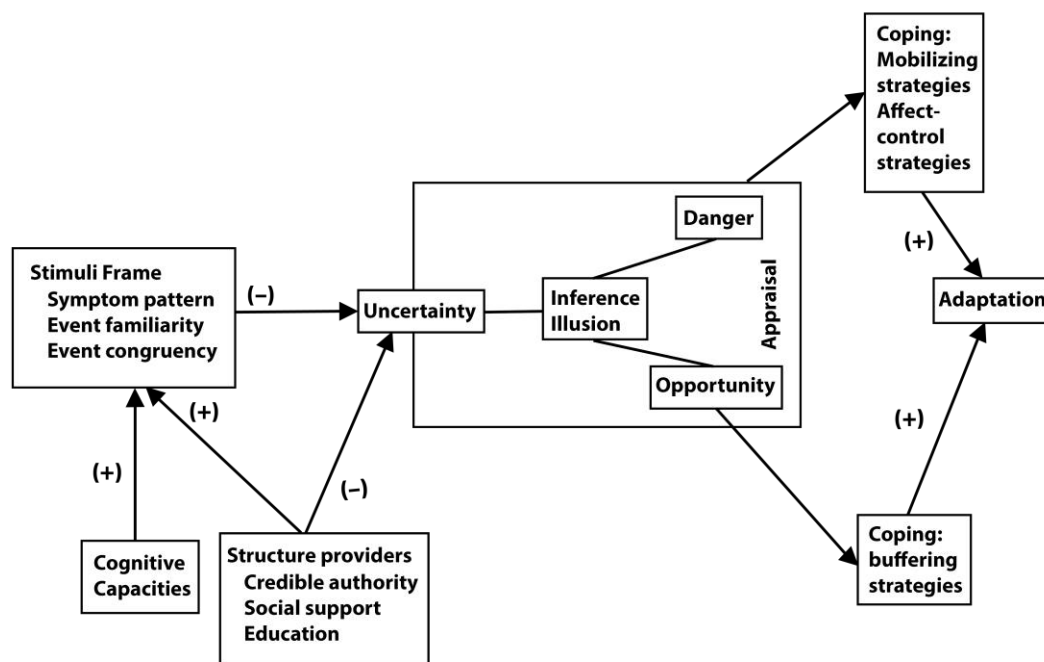


Figure 9. UIT/RUIT Model. Mishel, 1988.

Additionally, Mishel (1990) added a figure to explain the Reconceptualized part of the RUIT in terms of the Chronic Illness Schema Model. Figure 10 exemplifies what happens when an uncertainty is appraised as a danger and then is viewed as an opportunity; a new view of life is attained. The schema below illustrates the process—the uncertainty causes instability; it is viewed as a danger. The jagged lines indicate invasion of uncertainty and instability, the circular portion indicate reorganization and

restructuring of the uncertainty, and the arrow means the process happens over time.

Eventually, a new view of life is constructed.

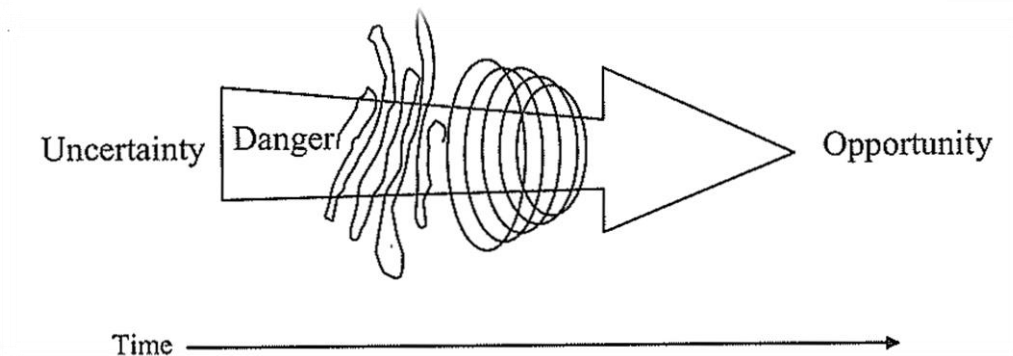


Figure 10. Uncertainty in chronic illness model. Mishel, 1990.

The Reconceptualized Uncertainty in Illness Theory has five dimensions: the antecedents, appraisal, coping, self-organization, and probabilistic thinking. The goal of the reconceptualization of this theory was also “to determine the meaning of illness-related events, inclusive of the inability to assign definite value and/or to accurately predict outcomes” (Unson, Flynn, Glendon, Haymes, & Sancho, 2015, p. 440). The RUIT is used in both quantitative and qualitative research studies.

Definitions of terms related to RUIT include:

- Antecedents of uncertainty – anything that occurs prior to the illness experience that affects the person’s thinking such as pain, prior experiences, and perception
- Appraisal of uncertainty – the process of placing a value on the uncertain situation
- Coping with uncertainty – activities that are used in dealing with the uncertainty
- Self-organization and probabilistic thinking – address living with the uncertainty of a chronic illness and its ongoing management or with an illness that occurs, which is the RUIT section. These two dimensions are spoken of but are not listed

on the model. Self-organization and probabilistic thinking are addressed under the coping with uncertainty of illness theme of the theory.

- Self-organization – begins with integrating continuous uncertainty into one’s self-structure that leads to the formation of a new sense of order for oneself with the result that uncertainty becomes a natural rhythm.
- Probabilistic thinking – is a belief in a conditional world in which the expectations of uncertainty and predictability is abandoned (Mishel, 2010).

In the model, four factors affect the person’s development of a new perspective of life: prior life experiences, physiological status, social resources, and providers of health care. Adaptation or adjustment represents the continuity of an individual’s usual bio- psychosocial behavior and is the desired outcome of coping efforts to either reduce uncertainty appraised as a danger or maintain uncertainty appraised as an opportunity. The RUIT is important to person, health, environment, and nursing (Mishel, 1990, 2010; Unson et al., 2015).

Three major themes are associated with the RUIT which are the antecedents, the appraisal, and the coping with uncertainty. Additionally, there are five dimensions of the RUIT include the antecedents, the appraisal, and the coping with uncertainty plus self-organization and probabilistic thinking. The additional two dimensions are not listed in the RUIT Theoretical Model. The antecedents of uncertainty theme include the stimuli frame, cognitive capacity, and structure providers. The signs and symptoms triggering the uncertainty are identified in the antecedent theme. These signs and symptoms might be unpredictable, and their outcomes might be ambiguous. The second theme of the RUIT refers to the appraisal of uncertainty. This section includes the phenomenon that is

creating the uncertainty, the appraisal of danger versus opportunity of the uncertainty, and the inference of the illness. The third theme of the RUIT refers to the coping mobilizing strategies, the adjustment, and the coping buffering strategies. Within the third theme of the RUIT lays the process of adaptation. Although this model seems linear, the individuals are constantly reevaluating their circumstances and the uncertainty; this process could be repeated several times based on symptoms and/or new information (Mishel, 2010). Through the use of probabilistic thinking and self-organization, adaptation is achieved, and adaptation can be re-assessed at any time based on new information. A new view of life or the phenomenon is established.

In this inquiry, the MCI syndrome carries a level of uncertainty and ambiguity since MCI could have many implications. To some of the participants, MCI implies a certain level of impending menace or possible lack of resolution. Most of the participants have not seen too many cases of individuals experiencing mild cognitive deficit; instead, some have encountered people with moderate to severe cases of dementia. When one is introduced to the disease at its end stage, the disease is at its worst; it is inevitable for the individual to form a negative perception and even fear of the dementia. Dementia is a progressive and debilitating illness.

The RUIT model is used to conceptualize the finding and themes of this inquiry. The antecedents of uncertainty theme include the stimuli frame, cognitive capacity, and structure providers. MCI is identified as a disturbance in cognitive capacity. The individual analyzed and explored the uncertainty as either a positive or a negative antecedent. In this model, the two antecedents are *blaming* and *stigmatizing – fearing*. The signs and symptoms triggering the uncertainty are identified. These signs and

symptoms could be unpredictable, and their outcomes could be ambiguous. The individual could use formal resources such as a nurse or doctor to investigate the problem. As previously indicated, any number of reasons could be factors causing the MCI. The MCI could be transient, or it might remain stable or it might worsen over time. Societal influences play a big role on the action of the person. Some of the individuals viewed this as a normal part of aging, and others know the MCI is not normal but are fearful of stigmatization and choose to not investigate.

The second theme of the RUIT refers to the appraisal of uncertainty. In this phase, the individuals were *doubting* their appraisal of the situation. Most were misinformed and were not equipped with the adequate knowledge to properly assess the problem. Some used prior inference and lived experiences to make inferences of their situation to establish their appraisal of the situation. This section includes the uncertainty, the appraisal of danger versus opportunity, and inference of illness. The appraisal affirms an illness could be appraised as either a danger or opportunity. In this inquiry, *doubting* is viewed as the appraisal of the uncertainty, and it was viewed as a danger by most of the participants. If the event is viewed as a danger, the person has a tendency to avoid the event, use wishful thinking, and use other maladaptive coping skills to deal with the phenomenon such as the MCI. Factors such as life experiences, physiological status, social resources, and health care providers all influence the appraisal and the formation of the adaptation. Social support of friends and family is also important in this section. Social support, religion or spirituality, and positive outlooks are ways of positively coping with the MCI; a positive adaptive coping skill leads to acceptance, realistic appraisal, and effective instrumental strategies. A positive outlook

should lead to improved mental health. According to van Manen (1990), there is an ever-present degree of uncertainty that exist in an individual's life.

The third theme of the RUIT refers to the coping mobilizing strategies, the adjustment, and the coping buffering strategies. Within the third theme of the RUIT lays the process of adaptation. Eventually, the individual moves to the adaptation phase of uncertainty in illness where there is more tranquility regardless of whether the uncertainty is being assessed as a danger or an opportunity. Adaptation is achieved when probabilistic thinking is accepted as a natural rhythm of life. The participants with MCI viewed MCI as a normal process of aging, and they adapted with this uncertainty through the coping mechanism of praying. Life is continually in motion; hence, certainty is never absolute. In this inquiry, *spiritualizing* and *praying* were used as coping mechanisms. Some of the participants made adjustments in their daily routine to accommodate the changes in their memories such that some used calendars, friends, or set routines to cope with the MCI. According to Mishel (2010), people function in far-from-equilibrium states. Adaptation is used to reduce or maintain the uncertainty. During the period of adaption, some re-appraisal often occurs over time. Knowledge about the phenomenon and the treatment options are important aspects of the education process, and it is an opportunity for health care workers particularly nursing professionals to provide the appropriate information and intervention. The dissipation of knowledge is gravely necessary. Knowledge leads to reduced uncertainty.

According to van Manen (1990), meaning in any phenomenon is not simple and is not one-directional, meaning has many layers and is multi-directional. Many of the participants demonstrated their lack of comprehension of MCI, but they assigned

meaning to it based on their lived experiences. Self-organization and probabilistic thinking occur when appraisal and coping skills are adaptive. If the participant is able to formulate a new sense of order, then self-organization occurs despite the chaos that is present (Mishel, 1990). **Val** takes the same route every day, **Iranne** says the rosary, and **Pierre-Jacques** uses the calendar. If the participant can adapt to the uncertainty, then the probabilistic thinking dimension has been achieved. The participant is able to develop a new belief or a conditional belief in an ever-changing world (Unson et al., 2014).

To effectively understand the lived experience of the participants, the narrative stories of the participants were encouraged and elicited in depth. With phenomenology as the philosophical underpinning and a research design method, semi-structured interviews were conducted to capture a rich and in-depth account of the participants' lived experiences. Epoche was used to allow the participants to fully express their views without the influences of the researcher. The aim of this inquiry was to understand and to describe the essence of the lived experiences of the Haitians with MCI in South Florida. As evident by the rich descriptions of the participants, the nursing profession and other health care workers must understand the cultural beliefs and practices of Haitians in order to effectively address and provide effective health care services for the Haitian person with any mental health issues. The researcher used the RUIT Theoretical Model by Mishel 1988 to explain, comprehend, and represent the lived experience of Haitians with MCI in South Florida by using the derived themes and the connection to the RUIT (see Figure 11).

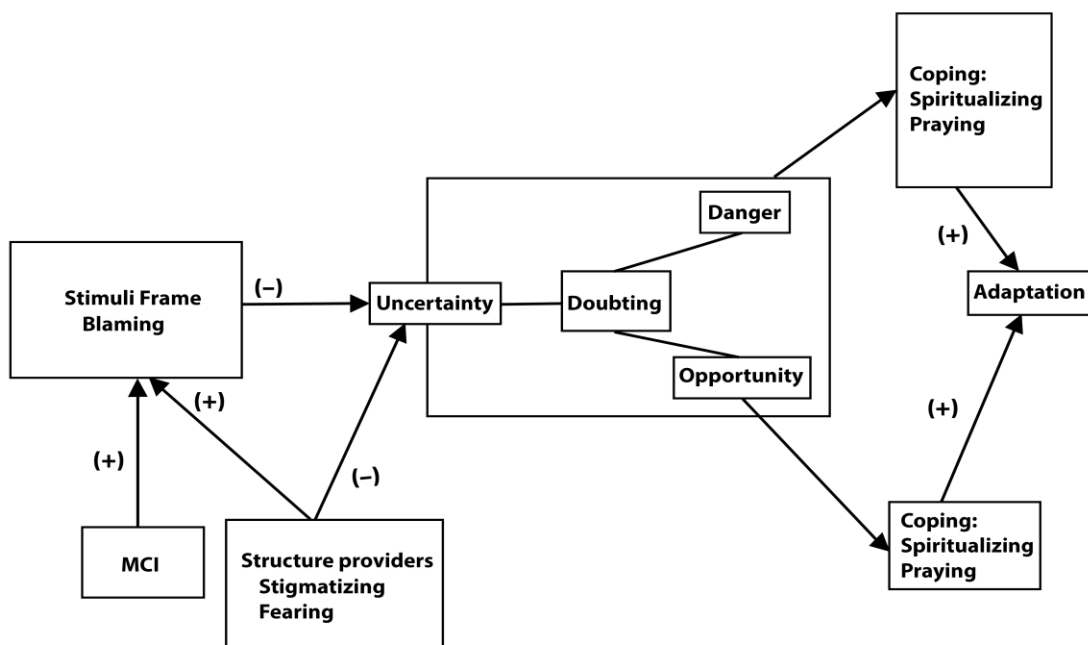


Figure 7. RUIT with MCI by Samson-Joseph (2016, adapted from Mishel, 1988).

The schema represents the lived experience of Haitians with MCI living in South Florida in conjunction with the RUIT (Samson-Joseph, 2016). The model illustrates the person having MCI in a time continuum. The model represents a natural process that all human beings experience; adaptation is a survival skill that could occur in any short- or long-term situation including during health or during illness. This theory is important to nursing because nurses can construct a personal scenario for the illness, as was done using the vignette for this study. The RUIT can assist with orientation and with comprehension of the disease process. RUIT can assist health care workers and patients in developing exercises on coping skill strategies, which could lead to adaptation (Mishel, 1990, 2010; Unson et al., 2015). The RUIT is useful in applying changes in practice, as a guide to health care providers, to alleviate patient's uncertainty, to determine better

patient outcomes, and in research studies. The aim of treatment with ethnic minority populations should be to empower clients to actively interact with their service provider. Any treatment plan for mental illness should encompass the spiritual and psychosocial approaches (Evans, 2016). Culturally responsive treatment plans should allow effective communication between the individuals and the service provider, allowing effective treatment and prevention plans (Nicolas et al., 2006). Western practitioners should avoid negative stigmatization of voodoo healing practices to avoid a dichotomy of treatment from the biomedical health model and the Haitian health belief system. The coordination of treatment could lead to better treatment adherence and better active participation of the individual in his or her well-being (Evans, 2016).

General discussion. These two topics were not consistent with any of the themes, but a few of the participants mentioned them in passing. **Val, Jean, Etienne, Chrisiane, Pierre,** and **Tet** all exercise in the morning when they rise. When asked to describe their days, they all started by saying, “I get up, and I exercise.” All of them perform different physical exercises, including running, weight lifting, bicycling, walking around the neighborhood, and going to the gym as means to remain healthy. Some of the participants mentioned their previous surgeries, which they believed contributed to their MCI. Two of the participants mentioned their meager financial status, which seemed to have been an important factor to them. Although prompts were used to attempt to keep the participants more focused on MCI, some wanted to discuss their life stories, and others told tales that were not related; some participants wanted to talk about issues such as how much they love their PCP and how they met their PCP or how kind or unkind the office staff is. These conversations were listened to attentively since the verbal releases

facilitated better communication about MCI. The belief of mind-body-spirit connection was strong. A harmonized mind-body-spirit is believed to create inner peace and to strengthen the faith of the individual (Byrne, 2010). Some of the participants empirically understood the positive association between good physical health and well-being and mental health. The Alzheimer's Association published a list of measures to prevent dementia most notably Alzheimer's disease. Diet and supplements, stress management with yoga and meditation, physical and mental exercises, and spiritual fitness (AA, 2005). These four components have been found to be effective against Alzheimer's disease formation. This approach combined both conventional and holistic models of health to make their recommendations. Chopra & Fisher (2016) explained that there five simple things people can do to live longer and healthier lives: "There is no doubt in my mind that drinking coffee, maintaining high but normal levels of vitamin D, exercising, taking a few minutes each day to meditate, and eating a handful of nuts is very good for you" (p. xi). The impact of these five modalities on health have been proven to be greatly incredible (Chopra & Fisher, 2016).

Significance of the Study

This study provided a rich description of the perceptions of the participants regarding MCI. The study gave a voice to the participants who were previously silent. In the United States, data about the Haitian experience with MCI is nonexistent; this study provided some information regarding MCI and Haitians. consequently, the data obtained from the study provided a greater understanding of MCI in this ethnic community. A better understand of MCI might contribute to better quality of life for future Haitian cohorts. If MCI is detected early, it is believed that intervention can be taken early which

could lead to better treatment outcomes. When the cultural beliefs of the individual are understood and healthcare is delivered accordingly, the quality of life of the individual is enhanced. Consequently, there are less treatment complications and less financial burden on the individual and their society.

Significance of the Study to Nursing Knowledge

This inquiry adds to the repertoire of scholarly nursing inquiry. This qualitative phenomenological inquiry is significant because it served to address the gap that exists in the literature about the lived experience of Haitians with MCI living in South Florida. Four main themes and two sub-themes were identified to describe the meaning and the essence of the lived experience. The themes could be used as guides during the nursing process. Recognizing culture influences regarding the health care beliefs of the individuals are key to providing culturally congruent care in all nursing processes. As the population of Haitians are growing in the United States, health care practices must be consistent with their belief system to effect positive changes. As indicated by Unantenne et al. (2013), “Health is powerfully influenced by cultural, social and philosophical factors, including meaning, purpose in life, and the quality of intimate relationship” (p. 1148). As nurses, we are aware of such nuances between belief systems and health. Using the four themes and subthemes of *blaming*, *stigmatizing – fearing*, *doubting*, and *spiritualizing – praying*, nurses can construct knowledge that adaptation during the uncertainty illness occurs in many ways, but adaptation allows the individual to thrive. When nurses allow the individuals to express their views or beliefs regarding a phenomenon, an outstanding nurse-patient relationship is borne; therefore, nurses can provide superior health care services for the individual.

Implications for Nursing Education

The results of the study could guide nursing curriculum development. As evidenced by the finding of this inquiry and as affirmed by Colin (2009), culture influences the health care needs of the individuals in various cultural groups. To reduce health disparity, a culturally competent course could be included into the nursing curriculum. Health care is continuously changing; there are new concerns and issues evolving every day, and with rapid changes, adjustment can be difficult. Nevertheless, the nursing profession must remain competent and modernized. It is communicated that spirituality is the most neglected aspect of clinical practice. There needs to be a restructuring of all nursing education to include spiritual care as part of the curriculum, not only during the end-of-life care setting, but throughout the entire spectrum of nursing care services. Clearly, not all settings must have a spiritual base, but at least the nurse will be well versed in patient concerns and belief systems. The implications for the future of nursing education are that holistic nursing practices should be incorporated in congruence with the biomedical system for all individuals. Nursing education needs to be evaluated and revised continually to meet the demand of an ever-evolving health care system and patient concerns. Continuing education modules regarding the uncertainty of illnesses and the effects of uncertainty on the individual are also needed for nurses who are not currently in school. Cultural integration is essential for the success of health care systems (Welch et al. 1998). Additional, educational programs for healthcare providers about the topic of stigmatizing regarding MCI, Dementia, and mental illness could be established. These educational programs could be provided in a train-the-trainer format.

Implications for Nursing Practice

Understanding the perspective of the person diagnosed with MCI should enhance health care services in any setting such as acute care environment, physical therapy, surgery, and mental health settings. The quality of life of the patients might be positively affected since the health practitioner now have a richer understanding of MCI from the individual's cultural perspective. The health care practitioner should take into account that stigmatism and fear regarding mental illness could deter the individual from seeking or accepting health care services. Understanding the culture may help the nurse to develop better interventions to meet that population's needs. Patient care outcomes might be more positive if the nurse is culturally aware and sensitive and is aware of the uncertainty and the doubt associated with the MCI syndrome.

Adaptation encompasses the appraisal of perception, beliefs, and sentiments that are both negative and positive. With the adaptation comes self-organization and probabilistic thinking. Acceptance and seeking to improve an individual's locus of control became paramount with the adaptation of the Haitians with MCI living in South Florida. The biomedical health care model often ignores the congruency between spiritual beliefs and the health practices of individuals. Such connection is essential. Spirituality and praying are seen as private acts and get separated from the person in certain nursing practices (Unantenne et al., 2013). Yet, in hospice services, nurses provide spiritual care readily. Otherwise, spirituality is often times neglected in clinical practice. Nurses could direct educational seminars to educate the individuals and their family members on the disease pathologies, the disease process, and treatment options available. Furthermore, nurses should be empowered through education to recognize the

dimensions of uncertainty and to assist the individuals affected to be able to cope with the effects of uncertainty in illness (Mishel, 1990). One example is that since MCI or dementia is unpredictable, a nurse guided education and support system through counseling could decrease stress and anxiety associated with the uncertainty of the individuals and their families.

Implications for Nursing Research

A lack of research on mental health exists, especially dementia on the Haitian population in the United States. Few qualitative studies were conducted in Haiti, but it is perceived the insights of the participants in the United States versus Haiti might differ. Further, more research studies need to be conducted with people with MCI, dementia, and their caregivers. A research study conducted by Nicolas et al. (2006) with affected individuals provided a rich and priceless account of the person's experiences. Nicolas et al. (2006) wrote:

We believe that this new awareness will motivate clinicians and researchers to use their clients' (and their clients' families') perspectives on the etiology and treatment of illnesses to make the treatment process more consistent with the clients' needs. An important aim of treatment with ethnic minority populations should be to empower clients to actively interact with their service provider. (p. 706)

More research is needed to explore the lived experience of individuals in the United States and Haiti to understand the spectrum of health including health-seeking behaviors (Wagenaar et al., 2013). This study provides insights into the perception of the 21 participants with MCI in South Florida, but there are many Haitians throughout the

United States, and perhaps their perception differs. A few participants requested more research on the issues on mental health and cognitive impairment. This researcher concludes that more research studies are imperative since this topic appeared to be important to the participants and their communities as exhibited by their request for further investigation and knowledge. This study should be replicated in Haiti to understand the lived experiences of Haitians with MCI living in Haiti. Furthermore, an interventional study could be conducted to determine the effects of an educational program regarding MCI and dementia on the Haitian community, this could be a longitudinal study.

Implications for Health/Public Policy

As the population is growing older, so are the Haitians in the United States. This aging population will need specific care geared towards their cultural needs. The decision-makers need to understand and be aware of evidence-based research to demonstrate the needs of the population. The information obtained from this phenomenological inquiry could guide policy makers' decisions regarding these disenfranchised cohorts of Haitians with MCI in the United States. The nursing profession needs to be involved in all steps of decision-making and policy making process to ensure a fair distribution of resources for all cultural groups. Mental health and mental illness issues have been neglected in all society. The outcome of this inquiry provided data that raise awareness that more community-based information is needed and is being requested by the participants in their language. This study raises awareness about Haitians with MCI not only living in South Florida but also everywhere Haitians live. To provide quality health care to this group of individuals, health policy must be

changed to support the growing changes of the population. The results could affect legislation to provide more funding for educational and mental health services to the Haitian in South Florida.

Strengths/Limitations of the Study

The strengths of this qualitative inquiry include the rich and enormous amount of data obtained from the participants on their lived experiences with MCI in South Florida. Another strength of the study is the fact that a large group of individuals participated, which provided a rich description of the phenomenon. The other strength is that all of the participants who were 55 years and older, which brought wisdom to their experiences. The rigor of the study establishes strength.

One limitation noted with the study is that a reasonable number of potential participants contacted the researcher to participate in this study, but they were not accommodated. A triangulated study could have been beneficial; triangulation could be done to survey a larger group of individuals with MCI, and the results could have been generalized to the population. The understanding is that this community of Haitians in South Florida are willing and asking for more research involvement. Transferability is not feasible since the results reflect only the subset of participants. Another limitation is that the nature of the study involves participants with mild cognitive impairment, which could unintentionally affect the accuracy of the memory and event recalls. The researcher being a novice could be another limitation since she does not possess the advanced knowledge to conduct such an inquiry. Only Haitians were studied, which presented another limitation; other ethnic groups might have had different perceptions of MCI. A possible limitation was that the participants might have participated for the

token of appreciation. It was possible in their politeness that participants attempted to embellish their responses to please the researcher. The last limitation was the use of prompting due to cultural beliefs about Alzheimer's disease. The words Alzheimer disease or mild cognitive impairment do not exist in the Haitian language, so other signs and symptoms of the syndrome had to be described, which could have been misconstrued.

Recommendations for Future Research

This inquiry regarding the lived experience of Haitians in South Florida should be replicated in different parts of the country and in Haiti to understand more in depth the meaning and the essence of the lived experiences of Haitians dealing with MCI. The inquiry should also be replicated using different Caribbean groups to obtain a more ethnically diverse view of the experiences of persons with MCI. The recommendation for future studies would be to conduct a quantitative study regarding the factors that are affecting the adaptation. Another recommendation would be to explore spirituality aspects of uncertainty in illness more in depth. In addition, consideration should be made to include younger Haitians and post-earthquake victims and their families into the sample size. A longitudinal study would be beneficial since it would help the nursing profession to follow through and possibly understand the experiences over time. The experiences of family and caregivers would be beneficial to the overall care and to contribute to the body nursing knowledge. Interventions could be formulated to assist the individual with the disease process. Continued and ongoing education of new nurses could be improved with study results, especially regarding spirituality and nursing care. Overall, the results could help the nursing profession in general in areas of research,

education, policy-making, and nursing practice. As stated by Desrosiers and St. Fleurose (2002), “Understanding aspects of Haitian culture will facilitate mental health treatments” (p. 508).

Summary and Conclusion

In this chapter, the findings of this phenomenological inquiry regarding the lived experience of Haitians with MCI in South Florida were discussed. One gap in the literature is filled. Twenty-one older Haitian men and women volunteered to participate in the inquiry through purposive and snowball sampling methods. From the data generated from the participants, four themes and two sub-themes (*Blaming, Stigmatizing – Fearing, Doubting, and Spiritualizing – Praying*) were identified during the data analysis process. Based on the experiences of the participants with MCI, most were able to adapt or adjust their perceptions to formulate a new view of life. The themes were derived from the narrative descriptions of the participants using Max van Manen’s six research activities to examine and to arrive at the conclusion of the data, which is the essence and the meaning of the experience. The Reconceptualized Uncertainty of Illness Theory by Mishel (1990) was used as a guide to conceptualize the four themes generated. The uncertainty in illness theory is used to explain how individuals structure meaning for events of uncertainty in their lives. The uncertainty in illness theory becomes the driving force and the illness itself is accepted as reality (Mishel, 1990). According to Mishel, nurses can play a pivotal role in reducing the amount of uncertainty in illness by providing education about illness and by researching the reason for such uncertainty. It is understood that not all uncertainties can be eliminated since human beings are constantly evolving and changing. Not all situations are predictable in life according to Mishel.

Humans are faced with many changes that must be overcome or adapted. At the end of the inquiry, two main essential factors were discovered. This phenomenological inquiry described clearly the essence and the meaning of the lived experiences of Haitians with MCI in South Florida, and it contributed to the body of knowledge in the nursing profession.

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APPENDIX A

BARRY UNIVERSITY IRB APPROVAL LETTER

Barry University

Division of Academic Affairs

Research with Human Subjects
Protocol Review

Institutional Review Board

11300 NE 2nd Avenue, Miami, FL 33161
P: 305.899.3020 or 1.800.756.6000, ext. 3020
F: 305.899.3026
www.barry.edu


Date: March 9, 2016

Protocol Number: 160218

Title: The Lived Experience of Haitians with mild cognitive impairment
in South Florida: A Phenomenological Inquiry

Meeting Date: February 17, 2016

Name: Ms. Marie Bernadette Samson-Joseph

Address: 

Faculty Sponsor: Dr. Jessie Colin

Dear Ms. Sampson Joseph:

On behalf of the Barry University Institutional Review Board (IRB), I have verified that the specific changes requested by the convened IRB on February 17, 2016 have been made.

It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection.

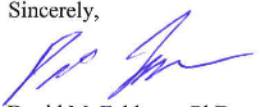
As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.

The approval granted expires on March 18, 2017. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with an IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Barbara Cook at [REDACTED] or send an e-mail to [REDACTED]. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,



David M. Feldman, PhD
Chair, Institutional Review Board
Barry University
Department of Psychology
11300 NE 2nd Avenue
Miami Shores, FL 33161

Cc: Dr. Jessie Colin

APPENDIX B Fòmilè Konsantman (CREOLE)

Inivèsite Barry

Nou envite w pou vin patisipe nan youn pwojè rechèch, Marie Bernadette Samson-Joseph, youn etidyan doktora nan Kolèj syans sante depatman Enfimri nan Inivèsite Barry ap fè. Tit pwojè a se "The Lived Experience of Haitians with Mild Cognitive Impairment Living in South Florida: A Phenomenological Inquiry" Objektif pwojè a se pou nou ka konprann pi byen opinyon Ayisyen sou pwoblem memwa. Nou bezwen youn maksimòm 25 granmoun laj 55 an oubyen plis. Si ou deside pou patisipe, nou pral mande w siyen youn fòm konsantman. Youn fwa ou dakò pou patisipe, nou pral mande w patisipe nan youn reyinyon avèk rechèchè. Pandan reyinyon an, nou pral mande w ranpli youn keksyonè demografik. Aprè ou fin konplete keksyonè a, nou pral fè ou rankont ak Marie Bernadette pou bay opinyon w sou pwoblem memwa. Sesyon an li ap dire anviwon inèd tan. Apgen youn deziem rankont pou verifies a nou te pale kap dire 30 minit. Nou pral anregistre konvèsasyon sa a epi nou pral mete li sou papye aprè sesyon an, men non w pap parèt sou papye a. Nou kapab kontakte w aprè pou verifye enfòmasyon ou te bay yo pandan rankont la. Konsantman w pou patisipe nan pwojè sa a se youn bagay volontè. Ou ka sispann patisipasyon w a nenpòt ki lè si w chwazi pou fè sa.

Nou pa konnen genyen okenn danje ki asosye ak pwojè sa a. Nap mande w chwazi yon ti non jwèt nou pral itilize pou identifye w sou papye a pou nou ka pi asire idantite w rete sekrè. Nou ap asosye tout repons ou yo avèk ti non jwèt sa a. Sèlman Anketè prensipal la ap okouran idantite w. Tout anregistreman ak fòmilè yo ap rete fèmen anba kle nan biwo Anketè a. Tout enfòmasyon elektwonik yo ap pwoteje tou avèk modpas. Si gen pou prezante osinon pibliye enfòmasyon ki soti nan pwojè sa a, nou pap idantifye w nan okenn fason. Nou ap kenbe fòm konsantman ou siyen an separeman de tout lòt enfòmasyon ou chwazi pataje. Aprè senk an nou ap detwi tout enfòmasyon.

Pa genyen okenn benefis dirèk pou w patisipe nan etid sa a, sepandan, enfòmasyon yo ka itil pou ede nou plis konpran opinion Ayisyen sou pwoblem memwa. Kòm youn jès apresyasyon, ou pral resevwa youn kado sou fòm youn kat Walmart ki gen 25 dola sou li nan pendan rankont la si ou dakò pou w patisipe. Si w gen kesyon, oubyen ou santi ou pa konfòtab sou nati etid sa a, silvouplè kontakte m, Marie Bernadette Samson-Joseph, pa telefòn nan nimewo [REDACTED] ou pa imel nan: marie.samson-joseph@mymail.barry.edu osinon doctè Jessie Colin, PhD, RN, FRE, FANN pa telefòn (305) 899-3830 ou pa imel nan jcolin@barry.edu; Si w gen kesyon sou jan nou trete w kòm youn patisipan nan etid sa a, silvouplè kontakte Barbara Cook, Institutional Review Board nan Barry Inivèsite, pa telefòn nan nimewo (305) 899-3020 ou pa imel nan bcook@barry.edu. Mwen deklare mwen te resevwa enfòmasyon sou nati ak objektif pwojè sa a atravè envestigatè prensipal la e mwen te li e konprann enfòmasyon ki prezante nan seksyon anwo yo, e mwen te resevwa youn kopi fòm sa a pou sèvi kòm dosye m. Mwen te gen opòtinite pou poze envestigatè prensipal la kesyon konsènan pwojè a. Mwen bay konsantman volontè m pou patisipe nan rechèch sa a.

Sinyati Patisipan an _____ Dat _____

Sinyati Envestigatè a _____ Dat _____

APPENDIX C**PERMISSION LETTER/ACCESS LETTER****February 19, 2016****To: Administrative Board**

My name is Marie Bernadette Samson-Joseph, ARNP, B-C, MSN/RN. I am a doctoral student at the College of Nursing and Health Sciences at Barry University in Miami, Florida. I am in the dissertation phase of my study.

The title of the study is “**The Lived Experience of Haitians with MCI in South Florida: A Phenomenological Inquiry.**” I am seeking information that will be useful in the field of nursing. The aims of the research are to understand and to describe the lived experiences of Haitians with mild cognitive impairment in South Florida.

I am requesting permission to post recruitment flyers in your facility after obtaining Institutional Review Board approval from Barry University. I would like to place the flyers in the common areas so that they are visible to the visitors.

If you have any questions or concerns regarding the study or you would like more information about my study, please contact me at [REDACTED] or marie.samson-joseph@mymail.barry.edu. or my research supervisor, Dr. Jessie M. Colin at (305) 899-3830 or by email at jcolin@barry.edu; or the Barry University Institutional Review Board point of contact, Barbara Cook, at (305) 899-3020, or email address bcook@barry.edu.

Thank you in advance for your cooperation and support.

Sincerely,

Marie Bernadette Samson-Joseph, ARNP, B-C
Barry University
College of Nursing and Health Sciences
Doctoral Student

APPENDIX C**PERMISSION LETTER/ACCESS LETTER****February 19, 2016****To: Clinician Services**

My name is Marie Bernadette Samson-Joseph, ARNP, B-C, MSN/RN. I am a doctoral student at the College of Nursing and Health Sciences at Barry University in Miami, Florida. I am in the dissertation phase of my study.

The title of the study is “**The Lived Experience of Haitians with MCI in South Florida: A Phenomenological Inquiry.**” I am seeking information that will be useful in the field of nursing. The aims of the research are to understand and to describe the lived experiences of Haitians with mild cognitive impairment in South Florida.

I am requesting permission to post recruitment flyers in your facility after obtaining Institutional Review Board approval from Barry University. I would like to place the flyers in the common areas so that they are visible to the visitors.

If you have any questions or concerns regarding the study or you would like more information about my study, please contact me at [REDACTED] or marie.samson-joseph@mymail.barry.edu. or my research supervisor, Dr. Jessie M. Colin at (305) 899-3830 or by email at jcolin@barry.edu; or the Barry University Institutional Review Board point of contact, Barbara Cook, at (305) 899-3020, or email address bcook@barry.edu.

Thank you in advance for your cooperation and support.

Sincerely,

Marie Bernadette Samson-Joseph, ARNP, B-C
Barry University
College of Nursing and Health Sciences
Doctoral Student

APPENDIX C**PERMISSION LETTER/ACCESS LETTER****February 19, 2016****To: Most Reverend Clergies**

My name is Marie Bernadette Samson-Joseph, ARNP, B-C, MSN/RN. I am a doctoral student at the College of Nursing and Health Sciences at Barry University in Miami, Florida. I am in the dissertation phase of my study.

The title of the study is “**The Lived Experience of Haitians with MCI in South Florida: A Phenomenological Inquiry.**” I am seeking information that will be useful in the field of nursing. The aims of the research are to understand and to describe the lived experiences of Haitians with mild cognitive impairment in South Florida.

I am requesting permission to post recruitment flyers in your facility after obtaining Institutional Review Board approval from Barry University. I would like to place the flyers in the common areas so that they are visible to the visitors. Also, I would like to address your congregation after a service to explain my study and to recruit potential participants.

If you have any questions or concerns regarding the study or you would like more information about my study, please contact me at [REDACTED] or marie.samson-joseph@mymail.barry.edu. or my research supervisor, Dr. Jessie M. Colin at (305) 899-3830 or by email at jcolin@barry.edu; or the Barry University Institutional Review Board point of contact, Barbara Cook, at (305) 899-3020, or email address bcook@barry.edu.

Thank you in advance for your cooperation and support.

Sincerely,

Marie Bernadette Samson-Joseph, ARNP, B-C
Barry University
College of Nursing and Health Sciences
Doctoral Student



APPENDIX D
RECRUITMENT FLYER

(English)



Greetings!

I am interested in people who are experiencing memory lapse!

If you are having or had a little trouble with your memory, I want to talk to you!

I am conducting a research to understand what it is like to experience forgetfulness

To be included in the study you must:

- ✓ **Be Haitian. You do not need to speak English.**
- ✓ **Be 55 years old or older. You do not need to know how to read or write**
 - ✓ **Live in South Florida**
 - ✓ **Have mild cognitive impairment.**

Call me!

Marie Bernadette Samson-Joseph of Barry University

[REDACTED] or email me at marie.samson-joseph@mymail.barry.edu

I am conducting a research study entitled:

The Lived Experience of Haitians with MCI in South Florida.

This research involves sharing your experience with memory problems. There will be two interviews: the first for 60 minutes, the second for no more than 30 minutes for a total of 90 minutes The interviews will be conducted face to face

Participation is voluntary, and all information will be held in strictest confidence.

You will receive a \$25 Walmart gift card at the beginning of the interview if you agree to participate and you meet criteria.

Barry University Institutional Review Board. Barbara Cook (305) 899-3020 or email at bcook@barry.edu.

Dissertation Chairperson. Dr. Jessie M. Colin (305) 899-3830 or email at jcolin@barry.edu



APPENDIX D

RECRUITMENT FLYER

(Creole)



Onè? Respè

Si-w gen pwoblèm memwa, “tèt pa la”

Si-w vle pale, nou kapab pale de sa

M-ap eseye Konprann sa kap pase lè youn moun pa kapab sonje byen

Pou-kapab patisipe nan rechèch sa-a:

- ✓ Fò-w Ayisyen. Ou pa bezwen pale anglè
 - ✓ Fò-w genyen 55 lane oubyen plis. Ou pa bezwen kon li ak ekri
 - ✓ Fò-w abite nan Sid Florid
 - ✓ Fo-w genyen “tèt pa la”
- Rele m!

Marie Bernadette Samson-Joseph nan Barry University

oubyen imel marie.samson-joseph@mymail.barry.edu

M-ap fè youn etid sou moun nan sid Floride kap viv ak pwoblem memwa ki rele:

The Lived Experience of Haitians with MCI in South Florida.

Nan etid sa-a wap gen pou patage eksperians ou nan rale memnen vini ke-w pral fe ak enfimye-resèch. Nou pral chita sou pwoblèm memwa nan de entevwou avek enfimye de resèch la.

Entevwou ap pral fèt fas a fas pou youn total de inèd tan avek 30 minit. 1er Entevwou-a ap inèd tan, dezyèm-nan ap preske 30 minit. Patisipasyon se sou baz volontè epi tout enfòmasyon ou bay ap rete sekre ant resèch a e ou min. Li pral konfedansyèl.

Nap bay \$25 kat Walmart a chak moun ki patisipe nan chita tandè sa-a si ou dakò pou w patisipe. Barry University Institutional Review Board. Barbara Cook (305) 899-3020 or email at bcook@barry.edu.

Dissertation Chairperson. Dr. Jessie M. Colin (305) 899-3830 or email at jcolin@barry.edu

APPENDIX E

DEMOGRAPHIC QUESTIONNAIRE

Demographic Data Collection Form

Pseudonym: _____

Date: _____ Time: _____

Age:

55-60___ 61-70___ 71-79___ 80-89___ 90-100___

Sex:

Female _____ Male _____

Marital Status:

Single___ Married___ Widowed___ Divorced___

Occupation: _____

Employment Status: Full Time ___ Part Time ___

Retired _____ Un-employed_____

Educational Level completed:

No schooling ___Elementary School ___Middle School ___High School

Some College/Technical School___College ___Graduate School ___

Religion:

How long have you been living in the United States? _____

Were you diagnosed with MCI?

If yes, when?

Did you have an illness that precipitated an MCI event?

Were you in the hospital?

If yes, when?

Other Diagnostic test or procedures?

APPENDIX E

Keksyon Demografik (Creole)
Fòm Pou Kolekte Done Demografik

Pseudonim/fonon: _____

Dat: _____ Tan: _____

Laj:

55-60___61-70___71-79___80-89___90-100___

Sèks:

Femèl _____ Mal _____

Ki gen rapò ak mariyaj:

Selibate___ Marye___ Vèv___ Divòse___

Metye: _____

Kondisyon Travay: Foul taym ___ Paktyam ___

Retretè _____ Chomè _____

Ki nivo edikatif ou:

San edikasyon/pat al lekòl ___ Lekòl elemantè ___ Lekòl mwayen ___

Lekòl segondè ___ Fakilte/Lekòl Teknik ___ Fakilte ___ Lekòl

Siperyè ___

Kwayans (Relijyon):

Depi kon byen tan ou nan etazini? _____

Eske yo te janm di w ke w gen pwoblèm memwa?

Si se wi, ki lè?

Eske w gen youn malady ki okazyone pwoblèm memwa?

Ou te entène nan lopital?

Si se wi, ki lè?

Lot tè eksaminasyon ak pwosede?

APPENDIX F

VIGNETTE (ENGLISH)

Lorencia is a 56-year-old Haitian produce merchant. She is a strong and vibrant woman. She is single head of house hold and she has 4 children: 2 Girls and 2 boys; three of whom still live with her which include Elizabeth 19, John 21, Jordan 23. Lorencia financially helps her brother's children and her cousins in Haiti. She indicates that nowadays, in addition to forgetting a few appointments, she is forgetting who her clients are and who owes her money. Most of the times, the business transaction is on a credit basis which means she provides the goods and in about a week or two the clients pay her for the goods. This is a credit system - the Caribbean way-- which is based on trust. There is no paper transaction during this exchange, the agreement occurs only through the word-of-mouth. Lorencia is beginning to lose money since some of the clients have come to realize that she is forgetful!

Lorencia is concerned so she visited her doctor recently because of this memory problem. In addition to the diagnostics and examination performed in the office, the doctor recommended some more diagnostic testing to be done at another location. Lorencia feels she is too busy trying to earn a living. She states that to have the diagnostic tests done customarily a trip to the doctor office or diagnostic centers involves her whole day. Lorencia does not have a car, as a result, she uses public transportation to those healthcare service centers which are not located in her neighborhood. Furthermore, Lorencia does not speak English. Lorencia is afraid that she will not be able to communicate properly with the healthcare workers and that she would have to ask one of her children to go with her to translate. Lorencia decided not to undergo the diagnostic testing since there are too many challenges involved. She has instead decided to pray and to ask God to help her with this problem. Because of the memory problem, Lorencia feels that her business is negatively being affected which in turn is causing her more apprehensions.

Appendix F

Vignette (Creole)

Lorencia se youn fanm Ayisiènn de 56 an ki vann tout kalite pwodwi. Se youn fanm vanyan. Pou kont li lap leve 4 pitit. 2 fi. 2 gason. Pami yo gen Elizabeth ki gen 19 an, Jordan ki gen 21 an e John ki gen 23 an. Yo toujou ap viva k li. Lorencia gen pitit frè ak kouzen'l lap sipòte an ayiti. Alè ki le, li deklare an plis ke li pa sonje apwontman yo, men tou li pa sonje ki moun ki achte nan men li alevwa pou'l ta sonje kantite lajan yo dwe'l. Le pli souvan se kredi li vann; ki donk, li pa vann lajan kontan. Sistèm sa a se youn sistèm kote tranzaksyon fèt sou baz konfians. Kote kliyan an ak machann nan gen youn akò vèbal. Alè kile, Lorencia ap pèdi lajan adwat agosh paske moun yo relyalize li gen difikilte pou'l sonje.

Enkyetid sou pwoblém, fè Lorencia al vizite Doktè'l. an plis ke dokte-a fè tout kalite tès nan ofis la, li rekòmande lòt kalite tès dyagnostik ak ekzaminasyon nan lòt ofis. Lorencia santil trò okipe ap chache lavi pou'l jwenn tan pou'l pase tout youn jounen ale ka Dòktè. Lorencia pa gen machin, konsa se transpò piblik li itilize pou'al pran swen la sante. Anplis, Lorencia pa pale anglè. Li pè paske li pap ka kominike ak travayè Lasante yo. Plis ankò fòl al mande youn nan ti moun li yo pou yo ale tradui pou li. Aprè tou sa, Lorencia deside pou'l pa ale fé okenn tès dysgnostik. Pwiske li pa ale lal priye bondye edel ak problém li yo. Ak tout pwoblém memwa say o, Lorencia santi ke tikomès la ap fè eshèk, a kòs de sa li genyen plis tèt chaje.

APPENDIX G**INTERVIEW QUESTIONS AND PROMPTS**

(English)

Primary Questions:

“What do you think about Lorencia’s story”?

“What is it like for you to experience MCI?”

“Tell me what is your day like.”

Prompts:

- What was it like when you first noticed this problem?
- What feelings come to mind when you think of this problem?
- How would you describe problems?
- Can you give me one word that would describe how you feel?
- Is there anything else that you would like to add?
- Tell me more...
- What happened next...?
- How long...?

APPENDIX G

INTERVIEW QUESTIONS AND PROMPTS

(Creole)

Primary Questions:

“Sa-w panse de istwa Lorencia-a”?

“Kouman ou santi-w le-w pa ka sonje oubyen ou bliye as ou tap di or fe?”

“Le konsa kouman ou pase jonen-w?”

Prompts:

- Premye fwa ou te santi pwoblem sa-a kouman sa te ye?
- Sak vin nan tet ou le-w ap panse ak pwoblem sa-a?
- Kouman ou ta ka dekri pwoblem sa yo?
- Eske-w ka ban-w youn mo ki di tout sa-w santi?
- Pa gen anyen ank ke-w ta renmen di-w?
- Di-m plis toujou...
- Sak rive apre sa...?
- Pou konbyen tan...?

APPENDIX H

INTERVIEW GUIDELINE

Date: _____ Time: _____

Pseudonym: _____ Contact Number _____

Introduction:

Thank them for their time
 Explaining the purpose, risks, and benefits, and the length of the interview
 Answer any questions or concerns
 Participant chooses to participate and meet criteria
 Give \$25 Walmart gift card

Participants' Rights:

The right to withdraw from the study at any time, and none of their information would be used.
 They may decline to answer any question
 May request to stop the recording device stopped. If they do, the information will still be used unless they withdraw altogether.
 May take a break at any time

Interview:

Choose a pseudonym for the interview to protect the confidentiality of the participants.
 Sign the consent.
 Complete questionnaire
 Request permission to start the interview and start audio-tape the recording
 Conduct interview, using prompts, paying attention, and avoiding distractions

Conclusion:

Ask participants if there is anything else they would like to discuss
 Make request for follow-up interview, and verify contact information
 Offer availability by phone or email, and encourage the participants to share with you anything that reflects their experience.
 Repeat assurances of confidentiality
 Thank you them for their time

Post Interview:

Label audiotape
 Complete field note reflection
 Begin transcription

APPENDIX I
ACCESS LETTER



Mil - Lake Health Care Center, Inc.

David Abellard, M.D.
General Medicine

Gina Joseph, M.D.
Board Certified Internal Medicine

Jean-Michel Lamour, M.D.
Board Certified Internal Medicine
Board Certified Medical Oncology
Sickle Cell & Hematology

Lydie Pierre-Louis, M.D.
Board Certified Family Medicine

Yvrose Archange, M.D.
Board Certified Internal Medicine

Gracia Lebrun, M.D.
Internal Medicine

Josie Jn Gilles, M.D.
Board Certified Pediatrics

March 28, 2016

Marie Bernadette Samson Joseph, PhD (c)
Barry University

Dear Ms. Joseph,

This is to confirm that Mil Lake Health Care Center is pleased to collaborate with you on your doctoral research project "The Lived Experience of Haitians with Mild Cognitive Impairment in South Florida: A Phenomenological inquiry". Lesly Auguste, PhD (c), RN-BC, our quality improvement program director will be available to assist you.

I have had the opportunity to discuss the research project with you and to ask for clarifications. According to our agreement, the research activities will be carried out as discussed in the proposal reviewed. Please consider this communication as our letter of cooperation. I look forward to working with you.

Sincerely,

David Abellard, MD
President
Mil Lake Health Care Center

c.c. Lesly Auguste

VITA

Marie Bernadette Samson-Joseph

marie.samson-joseph@mymail.barry.edu

PROFESSIONAL SUMMARY

Advanced Registered Nurse Practitioner, Board Certified

CREDENTIALS

Board Examination (ARNP)	2005
Board examination (BSN) License, State of Florida	1997

EXPERIENCE

MCCI Medical Group/ARNP <i>Home Program, Boca Raton, FL</i>	2012-present
ARNP – Facility NP <i>Heartland Care Partners, Boynton Beach, FL</i>	2010-2012
ARNP/Primary/Long Term Care <i>FLACs, South FL, FL</i>	2008-2010
ARNP – Facility <i>Evercare, South FL, FL</i>	2006-2008
Mixed Role/Hospice Supervisor/Clinical Manager <i>Hospice of Southeast/Manor Care, South FL, FL</i>	2002-2005
Delray Hospital and Manor Care Rehab/Staff Nurse <i>Staff Nurse Duties, South FL, FL</i>	1997-2002

EDUCATION

Master of Science in Nursing <i>Florida Atlantic University, Boca Raton, FL</i>	2005
Bachelor of Science in Nursing <i>Florida Atlantic University, Boca Raton, FL</i>	1997

AFFILIATIONS

Sigma Theta Tau International	1996-Current
Florida Nurses' Association	2005-Current
Haitian Nursing Association	2014-Current
American Association of Nurse Practitioners	2005-Current
Delta Epsilon Iota	2014-Current

COMMUNITY SERVICE

Community Educator <i>Community Outreach Center and Volunteering, Delray Beach to Miami, FL</i> Health Promotion. Healthy living teaching in community. Involved in Various Walks including MS, Breast Cancer, and Alzheimer's disease. Promoted daily activities to sustain positive attitude and quality of life for clients with dementias.	1996-Current
Poster Presentation at Lambda Chi Chapter Research Day at Barry University	Feb 25, 2015
