

2017

# Lived Experiences of African American Males with Fibromyalgia

Ethel Denise Perry  
*Walden University*

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# Walden University

College of Social and Behavioral Sciences

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Ethel Denise Callier-Perry

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2017

Abstract

Lived Experiences of African American Males with Fibromyalgia

by

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MA, Texas Southern University, 1985

BA, Texas Southern University, 1982

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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## Abstract

Fibromyalgia (FM) is a musculoskeletal and neurological disorder that causes constant pain, cognitive problems with short term memory, and sleep disorders. There are more females diagnosed with FM than males, and research has therefore primarily been conducted with females. Because little is known about African American males with FM, biopsychosocial theory was used in this phenomenological study to examine how African American males with FM are affected biologically, psychologically, and socially. Eight African American males diagnosed with FM were recruited from Houston, Texas and were interviewed about their lived experiences with FM, including experiences with the healthcare system, and how they used the internet to seek information about FM. Individual interview transcripts, conduct open coding, and thematic analysis led to identification of the following themes: (a) lengthy multiple medical evaluations to receive a diagnosis and various symptoms; (b) physical challenges, physical limitations, emotional issues, and cognitive issues experienced with FM; (c) limited physical and emotional support from family and friends; (d) hopeful about work and plans; (e) trust and confidence in healthcare providers and medical information obtained by asking questions; (f) limited internet search and not involved in online FM forums. The study showed that African American males with FM may experience debilitating symptoms and may use faith-based beliefs as one way to cope with FM. These results may bring positive social changes by providing caretakers with a better understanding of how FM affects the quality of life of African American males with FM, and provide new data to assist healthcare providers in diagnosing, treating, and serving this population.

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## Dedication

I dedicate my dissertation work to my loving parents, Professors JD and Vernice Callier whose words of encouragement and push for tenacity are deeply embedded in my heart.

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## Chapter 1: Introduction to the Study

### **Introduction**

The Centers for Disease Control (CDC, 2009) have estimated 5 million people in the United States 18 years or older have a diagnosis of Fibromyalgia (FM). The onset of FM usually occurs during middle age; about 90% of those diagnosed are females and 10% are males (CDC, 2009). Extensive research has shown how FM affects Caucasian males and females (Clauw, 2014), Hispanic males and females (Wolfe et al., 1995), and African American females (Schaefer, 2005), but there is a lack of evidence as to how African American males are affected by this disorder (Mogil, 2012). The purpose of the present study was to explore the personal accounts of African American males with FM in order to understand how the illness affects their quality of life.

FM is a painful musculoskeletal disorder that causes physiological problems for many individuals who are diagnosed with this debilitating disorder (Clauw, 2014). This illness is made up of many symptoms such as (a) morning joint stiffness; (b) consistent numbness and tingling in hands and feet; (c) migraines and generalized headaches; (d) non-restorative sleep; (e) cognitive disturbances causing short term memory problems; and (f) hypersensitivity to light, noise, and tactile stimuli (Clauw, 2009). There are several possible risk factors associated with the onset of FM including (a) encountering a stressful event such as a traumatic accident; (b) suffering repeated injuries, (c) experiencing reoccurring viral infections; (d) having a diagnosis of lupus, rheumatoid arthritis, and chronic fatigue syndrome (CFS); (e) having a family history of FM; and (f) being obese with a high body mass index (Clauw, 2009).

FM has a social impact that affects the person in physical, occupational, emotional, and economic areas (Wagner, Dibonaventura, Chandran, & Cappelleri, 2012). These issues can lead to the person with FM catastrophizing or ruminating over this disorder in a belief that the illness will cause them some permanent disability (Leung, 2012). The person diagnosed with FM may visit multiple internet websites seeking answers to FM health-related questions, and may join forum groups to gain support (Darez, MacDermid, Wilkins, Gibson, & Shaw, 2011). In Chapter 2, I detail the issues that the person with FM experiences.

The existing research has primarily been focused on females with FM, and there are far fewer studies on the lived experiences of African American males with this condition (Mogil, 2012). In the present qualitative study, I sought to fill the gap in the literature regarding how African American males are affected by FM.

### **Background**

Although researchers do not fully understand how hormones affect the central nervous system and pain (Yunas, 2011), they have speculated that FM is more prevalent in females because of biological gender differences. Females often feel a higher level of tenderness and pain because the hormone estrogen reduces the pain threshold and thereby place females at a greater risk of suffering (Yunas, 2011). The increased sensitivity to musculoskeletal pain leads to a female patient obtaining a confirmed diagnosis of FM through an assessment of 18 pressure tender points. These pressure points consist of pressing the neck bilaterally at the base of the skull, the front of the neck by the collarbone, both elbows, both hips, both buttocks curving to the upper thigh area, the

lower back bilaterally, both knees, the upper back around the shoulder blades, shoulders around the neck, and the sternum chest area (Yunas, 2011). Because of biological differences, males differ from females in their level of sensitivity to pain (Yunas, 2011). Males tend to exhibit less pain upon the administration of the 18 pressure tender points; yet males verbally express more pain overall than females (Yunas, 2011).

There are neurological symptoms associated with FM, such as sensorial pain, which are difficult for persons with FM to cope (Jain et al., 2003). The person may use positive or negative coping skills to manage the neurological symptoms that hyper-excitable nerves cause such as sensory discomfort of the auditory and visual senses (Jain et al., 2003). For example, the noises heard by individuals with FM are amplified beyond what is considered normal and lights appear too bright, leading to a level of irritability, sensorial pain, and discomfort (Lopez-Sola et al., 2014). The overloading of these sensory systems often causes the individual with FM to isolate themselves in their homes in a dark, quiet room, with as little stimulation as possible (Clauw, 2014).

Individuals with FM also demonstrate elevated levels of substance P, a neurotransmitter that relays pain and suppresses serotonin levels, which inhibit pain (Yunas, 2011). Yunas (2011) has noted that a person's genetics and hormones could be plausible indicators of FM.

FM has consequences for a person's social relationships because the individual is often not able to attend social events because of the exacerbated symptoms they are encountering day by day (Allaire, AlHeresh, & Keysor, 2013). Further, people with FM

are sometimes not able to keep up with job tasks at work and use leave time to the point of eventually applying for disability (Allaire et al., 2013).

Extensive evidence shows African American patients report greater pain and distress in comparison to Caucasians (Campbell & Edwards, 2012). For instance, when compared to Caucasians, African Americans reported higher pain in disorders such as joint pain, myofascial pain, and arthritis (Campbell & Edwards, 2012). Moreover, African Americans tend to be treated insufficiently for their pain compared to Caucasians (Green et al., 2005). African American males with FM are understudied, and it was therefore necessary to investigate this topic to provide new data to assist healthcare providers in diagnosing, treating, and serving this population.

### **Problem Statement**

The CDC (2009) has reported that African American patients with arthritis who have experienced high levels of pain often verbalize lesser tolerance for pain than Caucasian patients (Mogil, 2012). African American females with FM tend to have intense pain, deficits of cognitions that include fogginess and poor concentration, inhibited sleep leading to CFS, and a decline in socializations and strained relationships (Yunas, 2011).

African American males with FM tend to delay seeing their physician and are left undiagnosed because of (a) the belief that seeing a doctor portrays weakness, (b) having a level of mistrust of the medical community, and (c) the fact that healthcare providers may minimize their symptoms to the point the patient feels marginalized (Pellegrino, Waylonis, & Sommer, 1989). When there is a delay in seeing a physician, there appears



to be a greater risk of FM-related complications or problems that have consequences on employment, relationships, and general daily living (Pellegrino et al., 1989). McMillan (2011) reported that males struggle in seeking preventative treatment and often hold the false belief that males do not get sick. Thus, getting medical care at the onset of illness is delayed until the male is bedridden, and the symptoms are unbearable and unmanageable without medical intervention.

There are differences in how physicians may prescribe medications for males who present with physical pain. Caucasian males who seek care for physical pain often receive a prescription to treat the pain (Mogil, 2012). However, if the male is an African American with similar physical pain, the physician may recommend they obtain over the counter pain medications to help alleviate the discomfort (Mogil, 2012). Therefore, their pain may not be as well controlled as it might be with the prescribed medications that their counterpart receives (Mogil, 2012).

FM in African American males continues to be understudied, and researchers have not sufficiently explored the biological, psychological, social, and economic effects of FM on this group. There are prevalence and evidence data on African American males with other medical conditions such as rheumatoid arthritis and diabetes; however, none are available on FM according to Fibromyalgia Association of Houston Director G. Moses (personal communication, August 26, 2016). There are several possible reasons for the lack of prevalence and evidence data for this population with FM. First, African Americans, as compared to Caucasians, are less likely to have healthcare coverage, which is one of the prerequisites for having access to medical practices and participating in

some clinical trials (Swanson & Ward, 1995). Second, medical doctors may not believe their African American patients will follow the protocol that has been prescribed (Van Ryn & Burke, 2000). Finally, African Americans are less likely to have a primary care provider due to a lack of health insurance and are thus more likely to use the emergency room to obtain medical care. Typically, the emergency room doctor is not familiar with the patient; as a result, he or she would not consider enrolling these patients in a clinical trial (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997). Although researchers know that the pain reported by African American males is greater than other ethnic groups and females, there remains a gap in FM research on how FM affects African American males' quality of life.

### **Purpose of the Study**

The purpose of this descriptive phenomenological study was to examine the accounts of everyday lived experiences of adult African American males with FM. FM tends to be underdiagnosed in African American males. In this study, I have provided detailed information on how the lives of African American males with FM have been influenced by the disorder, how they cope with the condition on a daily basis, and how they interface with the Internet to help cope with FM.

### **Research Questions**

Research Question1 (RQ1): What are the lived experiences of African American males diagnosed with FM?

Research Question 2 (RQ2): What is the experience of African American males diagnosed with FM with the healthcare system?

Research Question 3 (RQ3): How do African American males diagnosed with FM utilize the internet to gather information about FM?

### **Theoretical Framework for Study**

I used the biopsychosocial theory (Engel, 1977) as the theoretical foundation of this study. In the biopsychosocial model, FM outcomes are understood as comprising three components. First, the psychological component is related to how depression and anxiety can be co-morbid with chronic musculoskeletal pain, primarily from a lack of sleep or interrupted sleep cycles due to the heightened pain (Jain et al., 2003). Second, researchers have associated the biological component with biomarker deoxyribonucleic acid (DNA) variations explicitly linked to FM, which could be a significant factor in causing increased musculoskeletal discomfort (Martinez-Jauand et al., 2012).

Researchers have also found a genetic FM trait known as autosomal dominant in FM patients and immediate family members (Martinez-Jauand et al., 2012). In FM studies, researchers have found that the hypothalamic-pituitary-adrenal axis (HPA) and sympathetic nervous system (SNS) are abnormal as to how the brain processes overactive pain signals (Martinez-Lavin, 2007).

Finally, the social component of the biopsychosocial model consists of life stressors that are experienced by individuals and that are often an important outcome factor of FM (Goldberg, Pachasoe, & Keith, 1999). Such psychosocial stressors experienced by individuals with FM may relate to a history of childhood abuse; these people will often verbalize a higher level of musculoskeletal pain and occupational stress,

which leads to poor sleep, bodily pain, and ultimately a diagnosis of FM (Kivimaki et al., 2003).

### **Nature of the Study**

In this study, I used a phenomenological research approach to examine how FM affected African American males. I interviewed African American males with FM who were 18 years and older. The responses I gathered from the interview questions were related to participants' lived experiences of living with FM. The verbal replies to the interview questions were coded and analyzed to identify themes. I selected the qualitative phenomenological design because it allowed me to capture the accounts of African American males with FM (Creswell, 2009). I conducted this study with the expectation that the findings will aid the medical community in better understanding the lived experiences of adult African American males with FM.

### **Definitions**

*Fibromyalgia (FM):* A musculoskeletal and neurological medical condition that causes heightened pain, body stiffness, dysfunctional sensory systems, cognitive impairments, abnormal sleep, depression, anxiety, and social relationship problems. It lasts for a minimum of 90 days (Clauw, 2014) and is diagnosed by an 18 point pressure point test according to guidelines set by the American College of Rheumatology (Yunas, 2011).

*Chronic pain:* A persistent ongoing pain that is specific to one body part or multi-wide pain to the body as a whole (Bond & Simpson, 2006). There is no relief for at least 90 days or more (Bond & Simpson, 2006).

*Chronic fatigue syndrome (CFS):* Conditions that include fatigue, pain, sleep difficulties, and cognitive problems (Pejovic et al., 2015). For a CFS diagnosis, the patient must verbally express that the primary symptom of exhaustion has lasted for a minimum of 90 days (Pejovic et al., 2015).

*Central Nervous System (CNS):* Part of the human physiological system that is composed of the brain and spinal cord (Staud & Spaeth, 2008). FM causes abnormalities in this system (Staud & Spaeth, 2008).

*Hypersensitivity:* A condition in which the sensory systems experience overload from environmental stimulation including loud noises, bright lights, tactile stimulants, and various smells (Jain et al., 2003).

*Catastrophization:* Maladaptive cognition where the person ruminates on the injury or sickness they believe will cause them harm and lead to an adverse outcome (Leung, 2012).

*Quality of life:* A particular level of health and comfort experienced by an individual on a daily basis that affects domains of life such as work, health, relationships, and family (Clauw, 2014).

*Disability:* A term that refers to being unable to work or perform daily living needs due to temporary or permanent physical limitations (Rivera, Esteve-Vives, Vallejo, & Rejas, 2010).

*18 point pressure point test:* A test of 18 points (9 pairs) in four quadrants of the body that feel pain when pressed: this pain may travel to the other body parts. This test is

part of the American College of Rheumatology guidelines, and a person must have at least 11 out of 18 tender points for an FM diagnosis (Yunas, 2011).

### **Assumptions**

The present study was based on lived experiences of African American males 18 years and older with a diagnosis of FM. My primary assumption was that these males with FM were capable of providing accurate accounts of their experiences for the purpose of observing how FM has affected their life.

### **Scope and Delimitations**

Participants in this study were African American males with FM 18 years and older who had experienced a decline in quality of life post-FM diagnosis. My research did not include individuals of any other ethnicities, females, or minors.

### **Limitations**

One limitation to this study was that I used participants who were African American adult males. Thus, this study is not generalizable to people of other ethnicities, females, or minors.

### **Significance**

In this research, I sought to provide insight into how FM has affected African American males 18 years and older, and to identify themes from their interview responses. My objective was to contribute to positive social change by providing a better understanding of how FM symptoms had affected the quality of life of African American males with FM. While conducting the research, I expected to capture specific themes that could be used to improve wellness prevention and education programs, decrease

medical costs, and improve the quality of life for the African American males affected by FM.

### **Summary**

Research has shown a higher level of pain intensity in African American males as compared to individuals of other ethnicities (Wilner, 2008). African American males tend to distrust the medical community, which often leads to the exacerbation of physical symptoms that are difficult to treat when they present for the initial doctor appointment (McMillan, 2011). The extensive FM literature has few studies on African Americans males, and there is a consistent lack of evidence on how FM affects their lives. Thus, there was a need to study how FM impacts African American males with this disorder.

Chapter 2 includes an in-depth overview of males with FM and African American males with FM. In Chapter 3, I outline the methodology I used for the study and discuss the interview instrument. Chapter 4 includes the results from this study, and in Chapter 5 I discuss the findings.

## Chapter 2: Literature Review

### **Introduction**

In the United States there are approximately 17.3 million African American males; these individuals make up 48% of all African Americans in the United States (Campbell & Edwards, 2012). African American males are more likely to have greater health issues than all other ethnic and gender groups (McNeal, Perkins, & Lyons, 2006). African American males also have the lowest life expectancy of all other ethnic and gender groups (McNeal et al., 2006).

FM is a condition that consists of widespread chronic musculoskeletal pain and usually presents in young or middle-aged females (Clauw, 2014). The research in this area has shown that those diagnosed with FM are 90% female and 10% male (Clauw, 2014). Most people with FM have a life filled with daily pain and fatigue, causing a decline in the quality of life associated with financial, social support, mental health, and employment difficulties (Clauw, 2014). FM is not a life-threatening condition, though those affected with this illness often worry if FM will lead to a more severe disorder such as Lupus (Clauw, 2014). There is evidence that African American males have the highest level of chronic pain as compared to individuals of other races/ethnicities (Campbell & Edwards, 2012). In a study assessing African American males for biological and oral feedback to discomfort, African American males routinely presented as highly sensitive to pain (Wilner, 2008).

There is a lack of research regarding how FM affects African American males. In this qualitative phenomenological study, I thus examined the lived experiences of African



American males with FM related to coping with the condition, health information seeking, their opinions of the healthcare system, and experiences with their primary health provider. The information collected in this study can be used for educational purposes and future strategies in developing continuing education training for healthcare providers on this topic.

### **Background**

In the early 1800s, doctors described FM as muscular rheumatism with symptoms consisting of stiffness, aches, fatigue, and problems sleeping (Wallace, 1999). A doctor in Scotland first noted the tender points that are specific to FM in the early 1820s, and by the early 1900s the term fibrositis was created to describe the inflammation that researchers believed to be the origin of pain (Wallace, 1999). In 1976, the name of this disorder was changed to FM because inflammation was no longer thought to be the reason for the pain (Wallace, 1999). The name of FM is derived from the Latin word *fibro*, meaning fibrous tissue, and the Greek words *myos* meaning muscles, and *algos* meaning pain (Wallace, 1999). The history of FM can be found in Appendixes A and B, which show the milestones that are foundational to FM.

### **Diagnosis of Fibromyalgia**

The American College of Rheumatology has two primary criteria that a patient should meet before a doctor makes a FM diagnosis. The two criteria are (a) that the patient must have exhibited constant pain in the four quadrants of their body for 3 months (Yunas, 2011), and (b) that the patient must have 11 out of 18 tender points on the 18-point pressure point test (Yunas, 2011). The test consists of pressing the neck bilaterally

at the base of the skull, the front of the neck by the collarbone, both elbows, both hips, both buttocks curving to the upper thigh area, the lower back bilaterally, both knees, the upper back around the shoulder blades, the shoulders around the neck, and the sternum chest area (Yunas, 2011).

A new clinical test that doctors may use as part of the diagnostic protocol is the FM/a blood test (Wallace, Gavin, Karpenko, Barkhordar, & Gillis 2015). FM/a is an acutely sensitive blood test used as an indicator of the presence of a specific marker made by the immune system blood cells that distinguishes FM from other conditions such as rheumatoid arthritis or lupus (Wallace et al., 2015).

### **Problem Statement**

FM is a complex illness that affects muscles, tendons, and ligaments (Yunas, 2011). Although FM is more prevalent in females, males are known to have this condition (Yunas, 2011). This disorder's pain is felt in soft connective tissues surrounding the bones and it shows no visible abnormalities upon a physical examination (Yunas, 2011).

To date, FM studies have not provided evidence of how African American males are affected by this condition. There are several reasons that African American males are not included in FM clinical research. First, African Americans when compared to Caucasians are less likely to have medical insurance, which is one of the prerequisites to access medical practices and enroll in some clinical trials (Swanson & Ward, 1995). Second, physicians may believe their African American patients will be non-adherent to the prescribed protocol in treating an illness (Van Ryn & Burke, 2000). Finally, African

Americans are high users of the emergency rooms due to a lack of medical insurance, and see multiple doctors with each visit. Because the doctors are not familiar with the patients, they do not consider them for enrollment in clinical trials (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997).

### **Males and Fibromyalgia**

Males experience FM and exhibit symptoms differently than females. The symptoms in males include lower tendon count, minimum depression, and reports of longer duration of symptoms (Yunas, 2011). Males' responses to the diagnostic tender point examination are lower than those of females because females are more sensitive to pain and have a greater response to the digital palpitation at pre-designated sites (Arnold, Clauw, & MacCarberg, 2011).

Over the past several years, physicians and specialists have begun to understand differences in male and female brains' serotonin system linkage to sleep, mood and other emotions, and pain-related functions (Yunas, 2011). During diagnostic preliminaries, females are often given a battery of tests and prescribed medications that males tend not to be considered for when they first present with symptoms (Mcnett et al., 2011).

This was a qualitative phenomenological study of African American males with FM. In my review of the existing body of knowledge on FM, I found that the study of African American males with FM is absent. I filled that gap by investigating how FM affected quality of life for African American males living with this disorder.

### Literature Search Strategy

I gather literature to review using the following databases: Access Medicine, Access Science, CLNAHL, Cochrane Library, DynaMed, Ebrary, ERIC (EBSCO host version), Global Health, Global Health Archive, Goggle Scholar, Healthcare Videos from Alexander Street Press, and HealthSource/Nursing/AcademicEdition. Other databases included: JAMA Evidence, KNODE, MEDLINE, Medline Plus, Walden Dissertations, PsycINFO, PsycARTICLES, PUBMed, ProQuest, Thoreau, UpToDate, Web of Science Psychology, A SAGE Full Text Collection, and SocINDEX with Full Text. The official websites of the National Fibromyalgia Association and the Rheumatology Association were also valuable.

I used the following search terms when searching these databases: *activities of daily living (ADLs), acupuncture, arthritis and rheumatism, attitudes/health/health personnel, behavior/modification/therapy, chronic disease/illness, chronic fatigue syndrome, clinical management/trials, cognition, cognitive therapy, and community health services. Other terms included: disease management, endocrine system diseases, epidemiology, etiology evaluation techniques, evidence-based medicine, exercise/tolerance, fatigue, fibromyalgia/fibromyalgia syndrome, functional evaluation/limitations/status, health promotion/status, holistic health, massage, Journal of Black Nursing, Journal of Neurology, Journal of Rheumatology, Journal of Men's Health, myofascial pain syndromes, mood disorders, muscle/pain, musculoskeletal diseases, and needs assessment.*

Keywords used to locate articles included: *nervous system diseases, substance p, neuralgia, neuromuscular agents, nociceptors, occupational therapy, outcome/assessment, pain/management/measurement/prevention, physical fitness/therapy, psychosocial aspects/factors, quality of life, African American males and fibromyalgia*. Other keywords include: *chronic pain and African American males, fatigue and African American male, fibro fog and African American males, musculoskeletal pain and African American males, quality of life of African American males with Fibromyalgia, and autoimmune disorders and African American males*.

There is little research on the lived experiences of African American males with FM. Therefore, I searched for information using the internet resources of various organizations including the CDC, the National Institute on Health (NIH), Black Men Health Initiative, the Arthritis Foundation website, the National Center for Chronic Disease Prevention and Health Promotion, the National Fibromyalgia Association, the National Fibromyalgia and Chronic Pain Association, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

### **Biopsychosocial Theory**

The biopsychosocial model (Engel, 1977) served as the theoretical foundation for this study. The biological component of this model includes the etiology of the illness and how it affects the human body. The psychological component of the biopsychosocial model addresses possible psychological agents for a health issue such as depression due to musculoskeletal pain, negative cognitions from lack of sleep, and lack of self-control over emotions. The social component of the biopsychosocial model includes how various

social elements such as one's financial status in society, cultural background, technology literacy, and theological beliefs can influence health. The degree of understanding of how each one of these areas can affect health is a determinant factor in how an individual learns to manage FM.

### **Biological**

Previous research proposes a strong familial background of FM may be a contributing factor of FM (Arnold et al., 2004). Subjects with FM have exhibited variations in a particular DNA sequence as referred to in medical terminology as the polymorphism genome (Buskila & Sarzi-Puttini, 2006). Vargas-Alarcon et al. (2009) conducted a study with 78 Hispanic patients with FM, who manifested persistent sympathetic over activity linked with a diminished abnormal activity to stress. The study concluded there was a relationship between adrenergic receptor (AR) gene polymorphisms and the probability of FM pathogenesis, and revealing increased chronic musculoskeletal pain as associated with the Hispanic with FM population who had a biomarker for DNA variations (Martinez-Jauand et al., 2012).

Pellegrino, Waylonis, and Sommer (1989) performed a study with 17 patients with FM and their immediate family members. Pelligrino et al. (1989) concluded that FM could begin at different points in life for the close related family members. The various points in life are known as the variable latent stage, where an individual may activate a defected gene at individually different ages (Pellegrino et al., 1989). One important finding from Pellegrino et al. (1989) is that a significant percentage of males with FM had a history of family members who were diagnosed with FM. Buskila and

Sarzi-Puttini (2006) confirmed this finding in a study with mothers with FM, along with their children. The researchers concluded 50% of offspring, whether male or female were at risk for developing FM if one or both parents had FM (Buskila & Sarzi-Puttini, 2006).

The person with FM has an atypical neuroendocrine system that harms the individual's biological stress network (Parker, Wessely, & Cleare, 2001). Parker et al. (2001) found that subjects with FM had abnormal hypothalamic-pituitary-adrenal axes (HPA), as well as sympathetic nervous systems (SNS). HPA and SNS are important components of the neuroendocrine system that controls responses to stress and interacts with pain processing at multiple stages. Martinez-Lavin (2007) indicated the SNS becomes overly active and renders the patient with FM helpless in reacting to various stressors. For many patients with FM, an abnormal sympathetic system may provide answers to impaired sleeping patterns, gastrointestinal problems, and increased levels of anxiety (Martinez-Lavin, 2007).

### **Psychosocial**

Stress in the workplace is considered as a high-risk factor associated with FM (Kivimaki et al., 2003). Occupational stress includes increased job tasks, being in a position that has no input in decision making, and bullying on the job. These identified stressors correlated to newly diagnosed cases of FM as noted by Kivimaki et al. (2003). As a result of the workplace stress, individuals reported symptoms of poor concentration and memory, physical aches and stiffness, feelings of irritability, anxiety, unbearable fatigue, feeling emotionally drained, and depression (Kivimaki et al., 2003).

Co-morbid with FM is depression. Walker et al. (1997) concluded that 90% of patients with FM had a history of psychiatric care, and the diagnosis of depression was more prevalent in patients with FM, than other rheumatic disorders. Research conducted by Okifuji, Turk, and Sherman (2007) demonstrated that depression appears to be a reaction to the pain experienced by the patient with FM.

### **Chronic Pain and Fibromyalgia**

Pain is a signal that notifies the brain that there is a malfunction at a particular site of the body. A person can experience pain psychologically or physically. Where the pain originates will determine how to treat the pain. How pain is experienced differs from person to person (Bond & Simpson, 2006). Pain is subjective to individuals, and the pain tolerance level varies from person to person. Pain falls into two primary categories, which are acute pain and chronic pain.

Acute pain is short lived, and the inception of the pain is instant. It is linked with a stress reaction that is associated with an elevated pulse and increased blood pressure, which leads to perspiration and paleness (Bond & Simpson, 2006). Acute pain responds to analgesia and therapeutics of the underlying complication (Hawthorn & Redmond, 1998).

Chronic pain is persistent and is encountered every day with little reprieve, and the beginnings of chronic pain can take place without a specific medical cause; whereby, frequently inducing depression and new conditions such as anxiety (Bond & Simpson, 2006). Chronic pain can result in various emotions and behaviors and affects how a person adjusts to and confronts their continuous distress, which is all part of chronic pain



management. In the boundaries of chronic pain, some individuals with FM will make every attempt to live a life that is normal as possible. In complete opposite, some people have turned to a reliance on others, for example, spouse, partner, immediate family members, social service agencies, or healthcare services, to assist with the issues associated with FM (Bond & Simpson, 2006).

It is crucial to evaluate non-malignant chronic pain in detail, determining its consequences to the person, their daily activities, the psychological effects, and the individual's comprehension of the chronic pain. The problem of not being able to find a diagnosis and solution to the chronic pain is discouraging, draining, and conveys an unfortunate stigma. Even a straightforward classification like neuropathic or nociceptive pain can bestow a feeling of validity and sense of control for people with chronic pain (Ruddere & Craig, 2016).

Nicholl et al. (2015) examined the relationship between depression and chronic pain within ethnic groups. The authors reported a higher occurrence of chronic widespread pain in ethnic groups in the United Kingdom, specifically at the rheumatology criterion musculoskeletal site two: low cervical bilateral, and sites three and four: second rib two-way at second costochondral. The study further noted that Hispanics and various Black ethnicities, versus Caucasians, self-reported higher musculoskeletal pain. United States minority ethnic groups who received medical treatment in pain clinics indicated to medical personnel that they had more chronic debilitating pain as compared to the American Caucasian population in the pain clinics (Nicholl et al., 2015). According to Nicholl et al. (2015), current research in the United

States seeks to understand the ethnic differences in chronic pain therapies, management, and questions whether access to healthcare is available. Attitudes and behaviors of persons with chronic pain are an important factor in providing explanations for some of the differences found in the study. Although Nicholl et al.'s (2015) research focused primarily on the relationship between depression and chronic pain, the study lacked information about the severity of pain. The severity of discomfort was not identified as a self-reported response from all of the ethnic groups in this study. The second limitation for Nicholl et al. (2015) research is the study failed to identify the gender for each ethnic group, as well as, noting if sex and race had a relationship in self-reported severe chronic pain.

Grieve and Schultewolter (2014) pointed out that chronic pain is best treated with a holistic approach and with the application of the biopsychosocial model. Chronic pain is associated with the soft tissues that are located outside the joints and the anatomic structures involved in the symptomology are muscles, ligaments, tendons, fascia, and bursae. All of these mechanical structures can feel painful to the patient with FM (Jain et al., 2003). The FM synovial joints are not affected directly as compared to the various arthritis disorders, where there is inflammation of the anatomic structures (Jain et al., 2003).

FM pain has been described by patients as feeling a burning sensation, followed by sensations of tingling in hands and feet, pain that globally travels through the body, stabbing pain, and searing sharp, deep aching pain (Jain et al., 2003). Jain et al. (2003)

clinically reference chronic pain with the medical makeup of allodynia (discomfort caused by a stimulus, such as a slight touch of the skin).

Chronic pain often causes increased fatigue, which leads to the furtherance of tiredness and suffering in the musculoskeletal system (Jain et al., 2003). The authors made mention that patients with FM lacked the supportive skeletal structure to uphold to the pressure that is caused by skeleton abnormalities. These different skeleton issues are found on the spinal discs and body joints, which is a primal response to the added weight or load pressure that is placed on the FM body. The spine of a patient with FM responds with pain, short and long durations of weight bearing activities, and often causes the patient with FM to spend more time sitting down or lying down from the relief of the bodily pain (Jain et al., 2003).

### **Fibromyalgia and Central Nervous System Origins**

The majority of the FM research outcomes often conclude a compromising of the central nervous system (CNS), which is made up of the brain and spinal cord (Staud & Spaeth, 2008). There is also supporting evidence of a malfunctioning in the muscles and connective tissue and the peripheral nervous system (PNS) which directly communicate with the CNS. Many researchers believe that the abnormalities that are found in the CNS and peripheral systems may contribute to the various body-wide symptoms (Staud & Spaeth, 2008). The body-wide symptoms the FM patient experiences could be associated with the pain-related chemical transmitters found in the spinal fluid are nerve growth factor, serotonin, substance P, norepinephrine, and corticotrophin releasing factor, which is all altered in the patient with FM (Staud & Spaeth, 2008). When all of these pain-

related chemical transmitters are changed, the levels of pain experienced by the FM patient are higher than for healthy individuals (Staud & Spaeth, 2008).

Patients who are diagnosed with FM brains differ in how they respond to pain when compared to individuals who are healthy (Abeles, Pillenger, Solitar, & Abeles, 2007). Diagnostic imaging of the FM brain has found that the mapping of the blood flow and the baseline thalamic metabolic activity are notably disrupted (Abeles et al., 2007). The investigators conclude that all of the anomalies in the CNS could be a factor of the chronic musculoskeletal pain that the patient with FM often experiences (Abeles et al., 2007).

### **Hypersensitivity to Non-Painful Events and Fibromyalgia**

The patient with FM's environment is filled with over stimulations from noises, smells, lights, and tactile, that leads to non-painful hypersensitivity stimulation (Lopez-Sola et al., 2014). Studies have used various techniques such as heat, chemicals, and electrical impulses to observe how a person with FM responds to pain (Lopez-Sola et al., 2014). These types of studies often demonstrate FM causing problems in being able to feel pain at decreased levels of stimulation when compared to healthy individuals (Lopez-Sola et al., 2014). Lopez-Sola et al.'s (2014) further emphasize that patients with FM have a greater sensitivity to heat, auditory, and tactile stimulations.

### **Catastrophizing and Fibromyalgia**

Pain catastrophizing is defined as a maladaptive cognition whereby the person ruminates on the injury or illness that they believe will cause them some danger and possibly lead to an adverse outcome such as lupus (Leung, 2012). When an individual

with FM experiences high levels of pain from compromising inflammatory disorders, this is an evident link to catastrophizing (Wilgen, Ittersum, Kaptein, & Wijhe, 2008). Boer, Steinhagen, Versteegen, Struys, and Sanderman (2014) also demonstrated a relationship between catastrophizing, increased pain elevations, distress, the urgency for objective feedback, a greater usage of over the counter (OTC) drugs, and lack of physical activity. Researchers reported catastrophizing behavior as an obsession caused from past experiences from authentic pain and or predictable pain (Boer et al., 2014).

Pain catastrophizing have been to be found more prominent in patients with FM than any other inflammatory disorders and often causes an avoidant anxiety response towards various levels of daily living and physical activities (Morris, Grimmer-Somers, Spottiswoode, & Louw, 2011). Often leading to high levels of depression and anxiety as observed in patients with FM who perceive chronic pain being more than what it seems to be and resulting in a state of catastrophization (Garza-Villarreal et al., 2014).

The study of Flink, Boersma, MacDonald, and Linton (2012) showed that catastrophizing and having a problem-solving attitude from a medical perspective had a direct correlation in patients with FM. Further explanations of this model mention that if the person with FM is constantly exposed to pain, they will worry more and perceive the pain from a medical stance, and will depend on medical answers from the healthcare professionals to find a solution for the pain (Flink et al., 2012).

### **African Americans and Health**

African Americans continue to lead the nation in having severe to chronic health issues (Lumpkins, Greiner, Daley, Mabachi, & Neuhaus, 2011). The religious institution

and the clergy in the African American neighborhood play a major role in raising the awareness and influence of health prevention campaigns and programs (Lumpkins et al., 2011). African American pastors tend to possess the belief that they can help the African American community by seeing themselves as promoting health prevention programs across the pulpit and having an impact on the attitudes toward health for those African Americans who are receiving minimum to no medical care (Lumpkins et al., 2011).

According to the United States 2010 census, African Americans are the second largest minority group and there is a growing concern of the high number of African Americans who are diagnosed with serious disorders on an annual basis (Lumpkins et al., 2011). The number of death rates for African Americans is disproportionate when compared to Caucasians in the areas of heart attacks, strokes and other cardiovascular disorders, colon, breast and prostate cancer (Lumpkins et al., 2011). Colon cancers and the various cardiovascular disorders are preventable health problems with early screening detection (Lumpkins et al., 2011). The African American religious institution is often observed as being an institution that is honorable and credible to many African Americans, and this leads to viewing the clergy as a guiding force in all areas of their life (Lumpkins et al., 2011).

African Americans' belief in a higher power has a direct relationship with health outcomes (Debnam, Holt, Crowther, Fouad, & Southward, 2012). A large number of African Americans frequently attend church services, and older African Americans' believe the religious institution is the primary source of support systems and social events (Debnam et al., 2012). When there is a significant level of church participation, evidence

has demonstrated that a person's higher power is believed to play a meaningful role in all areas of the African American life (Debnam et al., 2012). For both African American males and females, religious beliefs held was directly connected with lowered disorder prevention attitudes as demonstrated in daily consumption of vegetable and fruit servings, and when religious beliefs were not possessed, there was an increase in alcohol consumption, especially among African American males (Debnam et al., 2012).

Physical activity is a prevention treatment that has outcome measures of excellent health. Engaging in low to high-intensity daily exercise will lower the possibility of acquiring disorders such as obesity, diabetes, hypertension, cardiovascular disorder, cancers, depression, and dying at an early age (Leonard et al., 2013). Instead of the rewards that physical activity will provide, lower than 50% of the United States adult males and females exercise on a regular basis or do not engage in any physical activity (Leonard et al., 2013). African Americans are more susceptible to higher morbidity and mortality, demonstrating a need for wellness promotion programs that looks at moderate to vigorous exercise for this population (Leonard et al., 2013). In comparison to Caucasians, African Americans are found to have less interest in effective wellness programs that push for fitness activities and a high probability of not having health insurance coverage (Leonard et al., 2013).

Fallon, Wilcox, and Laken (2006) demonstrated that the number of medical office visits in the United States on a yearly basis for Caucasian American males and females combined was 334.6 visits per 100 people as compared to African American males and females combined, which was 252.9 visits per 100 persons. The discrepancy in medical

care and excellent health among African Americans has been speculated to be based on poor health, a decline in life expectancy, and barriers to acquiring healthcare when compared to Caucasians (Hewins-Maroney, Schumaker, & Williams, 2005).

### **African American Males and Medical Care**

African American males are considered to have the shortest life expectancy in the United States as compared to all of the other ethnic groups and genders (Hammond, Fleming, & Villa-Torres, 2016). African American males' lifespan is due to the prevalence of cardiovascular disorder, prostate cancer, diabetes, and other major illnesses (Hammond et al., 2016). This high mortality rates are due to biological, psychosocial, behavioral and elevated levels of stress, with outcomes of early death among African American males (Hammond et al., 2016). Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, (2010) research demonstrated that African American males procrastinate in receiving medical care and preventive clinical screenings such as blood pressure, cholesterol checks, and annual physicals. African American males often delay medical assistance after the onset of illness and the prognosis of the medical condition becomes challenging to the treating physician (Hammond et al., 2010). Because African American males are less likely to seek preventive care for their health, the African American male life expectancy is less than the Caucasian female of 11.3 years, African American female of 6.8 years, and Caucasian male of 6.2 years (Hammond et al., 2010). This life expectancy gap could be possibly reduced if African American males obtained preventive medical care as recommended by the medical community (Hammond et al., 2010).



Wade's (2008) research reported that the onset of illness in African American males could be expected to occur earlier in life and have a more severe disorder that has greater problems and less access to healthcare than Caucasian males. The rate of prostate cancer for African American males has soared because African American males do not tend to have a primary care physician that they meet with routinely, and they often feel uneasy about undergoing an examination for the prostate (McNeal et al., 2006). McNeal et al., (2006) reported that African American males of the ages 40 to 50 worried about possible cancer of the prostate.

Thirty five percent of African American males between the ages of 20 to 74 are likely to experience high blood pressure as compared to 25% of all males (McNeal et al., 2006). Moreover, due to human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), which was, in the year 2000 the principal three reasons of mortality for African American males ages 25 to 54 (McNeal et al., 2006). African American males, who are college age, are more likely to die as a result of, infection from HIV and other detrimental sexual transmitted disorders compared to Caucasian American college age men (McNeal et al., 2006). Other health issues related to shortened lifespan are college age African American males are more likely to die with leukemia, suicide, deaths that are by accident, and voluntarily participant or non-participant during violent happenings compared to Caucasian college age males (McNeal et al., 2006).

### **Quality of Life and Fibromyalgia**

FM is known to change the quality of life by deteriorating relationships, seclusion from family, friends, the public, decreasing work output in the areas of daily living activities, and impeding activities (Wagner et al., 2012). The quality of life is gravely affected by poor sleep hygiene, such as not being able to go to bed, waking up in the middle of the night, and unaware of falling asleep while at work or in public places (Wagner et al., 2012). The sleep difficulties have been paired with conflicting feelings and discomfort, which leads to a decline in physical functioning and affects the person with FM's quality of life (Wagner et al., 2012). Patients with FM express that their lives are interrupted and placed on hold due to pain and other symptoms that prohibit them from achieving the quality of life they had before the onset of FM (Wagner et al., 2012).

### **African American Males' Quality of Life**

There few studies on FM and how it influences African American males' quality of life. However, African American males are at risk for chronic disorders, which have been studied and, in turn, may provide insights as to expectations for African American males with FM. In this section, I will examine major depressive disorder and consciousness of race in African American males and quality of life.

**Major Depression Disorder.** Major depressive disorder among African American males is 5% to 10% more prevalent when compared to females, Hispanic males, and Caucasian males, and has a direct correlation with quality of life (Ward & Mengesha, 2013). The factors contributing to an impaired disabling major depressive disorder and quality of life for African American male compared to Caucasian male are:

Thirty-seven percent of African American males experienced elevated work stressors and impairment in the workplace than Caucasian males 28.9%. Forty-three percent of African American males experienced poor relationships as compared to 30.9% Caucasian males; and 55.4% of African American males had social problems in comparison to 34.2% Caucasian males (Ward & Mengesha, 2013). When faced with daily economic burdens, and various forms of discrimination for a particular period of time, the African American male's quality of life can be affected by (a) number of years of education. (b) Status of employment (underemployed, making minimum wage, unemployed with unemployment benefits, unemployed without unemployment benefits), and (c) highly stressed work environment and job duties. Finally (d) uncertain of job security (based on past job security experiences; Ward & Mengesha, 2013). Major depressive disorder affects the African American male's quality of life by co-occurring with illnesses such as hypertension, circulatory and heart problems (Ward & Mengesha, 2013). African American males are often concerned about the stigma that is perceived about mental illness and depression, whereby leading African American males to forgo seeking treatment for depression and further causing deterioration in their quality of life (Ward & Mengesha, 2013).

**Consciousness of Race.** The consciousness of race as a stressor still prevails in affecting the quality of life for the African American male (Brewer & Cooper, 2014). Race consciousness has been expressed as one having an anticipation of being threatened with the possibility of being discriminated against (Brewer & Cooper, 2014). This race consciousness has been correlated with elevated diastolic and systolic blood pressure

readings for African American males as compared to Caucasian men, whereby causing the quality of health for African American males to be compromised (Brewer & Cooper, 2014). Brewer and Cooper's (2014) findings revealed race influences access and quality of care for African American males receiving effective medical interventions for coronary artery disorders, such as cardiac catheterization, coronary artery bypass, and heart pacemaker, have a longer waiting time in receiving one of these effective therapies. This quality of life will affect the African American male in the areas of living with a declined health status, increasing the number of days off from employer, and heightened frustration level against the cardiovascular healthcare team, and primarily the physician (Brewer & Cooper, 2014).

### **The Effects of FM upon Family Dynamics**

There are few studies of the effects of FM upon family dynamics and how it influences males with FM's quality of life. I will examine how females with FM family dynamics are affected which, in turn, may provide insight as to expectations for males with FM.

FM is a chronic condition that affects the family dynamics in the areas of household duties, finances, and relationship problems with spouse, friends, and relatives (Soderberg, Strand, Haapala, & Lundman, 2003). FM not only impacts the person who is diagnosed with FM, but it also changes how the immediate family deals with a chronically ill person (Soderberg et al., 2003). An individual who has FM has complications in performing house chores and tends to withdraw from most free time events (Soderberg et al., 2003).

Spouses report that the work they now do around the home has doubled and their leisure time is no longer available (Soderberg et al., 2003). There tend to be financial modifications to the household budget, due to health expenses, and these changes will often cause added stress for the caregiver of the person with FM (Soderberg et al., 2003). Many spouses are placed involuntarily into the role of advocate on behalf of the FM person to try to obtain benefits and entitlements (Soderberg et al., 2003).

The adult family caregiver may experience symptoms of stress, situational depression, and anger for having the responsibility of taking care of a chronically ill family member, and changes in social outlets, which is minimal to none after the onset of FM (Soderberg et al., 2003). Without a support system in place for the caregivers of the person with FM, the caregivers often experience burnout and feeling as though there is no relief from the role of a caregiver (Soderberg et al., 2003). Having an average relationship is a past event, and now the healthy spouse and children must figure out their new normal life with a chronically ill family member (Soderberg et al., 2003). Attending the children's extracurricular activities and even attending family gatherings during the holidays is difficult for the person with FM, and the healthy family members must be able to process these changes, and how they will deal with the changes brought about by FM (Soderberg et al., 2003).

The healthy spouse tends to report that, with the onset of FM, the greatest loss was the changes in relationships with friends, relatives, and other social networks (Soderberg et al., 2003). Outsiders may find understanding the dynamics of living with a chronically ill person incomprehensible; therefore, these relationships failed to provide

support for the healthy spouse, and the relationship is quickly broken (Soderberg et al., 2003). Living with a person with FM slowly depletes the quality of life for not only the person with FM but also for the healthy spouse (Soderberg et al., 2003). Soderberg et al. (2003) showed that children are more adaptable to a parent with a chronic illness as compared to the adult family members.

Caregivers of the individual with FM may enter counseling to learn how to live with the new changes of living with a family member with FM (Preece & Sandberg, 2005). Therapists working with the family members of the patient with FM often focus on the level of resilience and hardiness expressed during the counseling session (Preece and Sandberg, 2005). Family therapy sessions are beneficial in strengthening the communication skills, teaching problem-solving techniques, and providing community resources (Preece & Sandberg, 2005). If the family lacks resilience and hardiness, the therapist may conduct building exercises during the counseling session to strengthen these two areas (Preece & Sandberg, 2005).

Caregiving can place a psychological burden on the healthy family members and further deteriorate the family structure (Richardson, Ong, & Sim, 2007). Individuals with chronic widespread pain will take on the sick person role, however with support from family, friends, counseling, and support networks (Richardson et al., 2007). People with FM can learn how to adapt positively to these changes caused by the onset of FM to help reduce the likelihood of deteriorating family dynamics (Richardson et al., 2007).

The person with FM often finds their healthy spouse experiencing a decline in physical and mental health (Steiner, Bigatti, Hernandez, Lydon-Lam, & Johnston, 2010).

Marital partners often report a particular level of marital dissatisfaction in living with a spouse with a chronic medical condition (Steiner et al., 2010). Research shows that when the individual with FM and their healthy spouse have a strong social support system; the new life of living with a spouse with FM is adaptable when compared to the healthy spouse and person with FM who do not have a strong social support system (Steiner et al., 2010). Marital dissatisfaction was found mostly among males, and females were shown to be the most reliable support system, which is usually seen in most marriages (Steiner et al., 2010). In most marriages both partners are each other's support system and when a spouse is diagnosed with an illness that ravages the body and strains the relationship, the other spouse often find it difficult to cope in the absence of a support system (Steiner et al., 2010). Support away from the marriage often provides relief from the added on home life stressors for the spouse diagnosed with FM and the healthy spouse (Steiner et al., 2010).

### **Employment Issues and Disability as Related to Fibromyalgia**

The onset of FM causes issues in being able to work at a job that may have high demands, fast paced, and project deadlines (Allaire et al., 2013). There is an increased possibility of resigning from a job or being released from the employer, both of which leads to unemployment (Rakovski, Zettel-Watson, & Rutledge, 2012). Evidence shows that when individuals with FM continue to stay employed, they keep their social networks at work and usually encounter less physical and psychological symptoms whereas the person with FM discontinues employment, additional mental suffering results (Rakovski et al., 2012).

The newly diagnosed employee with FM often has trouble with squatting, twisting, and coordination, which all are known to elevate discomfort in the body (Burckhardt, Liedberg, Henriksson, & Kendall, 2005). Many people with FM are given advice when first diagnosed, of what aspects of their workplace may worsen FM symptoms, and decrease work productivity (Rakovski et al., 2012). Patients with FM who perform manual labor found this type of work as being difficult to perform as well as jobs that were deskbound with repetitive movements (Allaire et al., 2013). Patients with FM have difficulties adjusting to working schedules that were not flexible and requested more time for projects to be completed (Allaire et al., 2013). Receiving support for an illness that no one can visibly observe has given credence for the employer not being supportive of the worker with FM, and this leads to further FM related work problems (Allaire et al., 2013).

The work environment is tolerable for the patient with FM when changes in schedules, such as arriving an hour later for work; and making their office equipment suitable for reducing musculoskeletal pain while typing or sitting for extended periods of time (Allaire et al., 2013). When work environments fail to make accommodations for the employee with FM, then the risk for seeking disability increases, whereas a simple plan could be put in place as an intervention to prevent disability and keep the worker with FM employed (Allaire et al., 2013).

The person with FM who experiences long-term unemployment is more likely to make application for benefit entitlements (Rivera et al., 2010). Before applying for long term disability, many of the patients with FM may have been on temporary work



disability where sick time is used under the family medical leave act for no more than 12 months (Rivera et al., 2010). If the patient with FM is still on family medical leave after one year, this leave will terminate, and the individual with FM is usually released from employment due to a chronic illness (Rivera et al., 2010).

### **Use of the Internet to Seek Answers and Support for FM**

Research demonstrates that more often females use the internet to search for health related information (Bidmon & Terlutter, 2015). Furthermore, Caucasians search the internet for health related information more often than African American males (Mitchell, Thompson, Watkins, Shires, Modlin, 2014). The lack of engagement in the internet for health related information may contribute to the African American males' health disparities (Mitchell et. al., 2014).

Individuals, who have been diagnosed with FM, often seek for answers, new medical treatments, research studies looking for subjects, become part of open forums, and new pharmaceutical products to treat FM, through viewing the websites on the internet (Daraz et al., 2011). The internet has its limitations, such as the websites visited may not have concise and clear education materials on health topics, and the advanced and better quality websites may have too advanced language and not comprehensible due to a level of reading or education (Daraz et al., 2011). In the year 2000, the number of persons searching for medical advice on the internet was 46%, and this took a growth to 61% in 2009 in the United States (Darez, MacDermid, Shaw, Wilkins, & Gibson, 2011). Individuals who are looking for health advice, often report regret in how poor quality of the information presented on these internet sites (Darez et al., 2011).

The person with health related issues found the medical terminology and statistical data presented, difficult for the reader to interpret, and the medical terms need to be defined or simplified to a language that all can be easily comprehended (Darez et al., 2011). Van Uden-Kraan et al. (2009) showed that when those who have a medical condition, search websites for information, they often will feel a sense of empowerment in being in controlled of their health, and feel as though they are collaborating with their healthcare team in providing input in the treatment plan.

### **Summary**

Limited knowledge is accessible on FM and how this medical disorder relates to African American males. The research reviewed in this chapter examined significant components, such as biological variations in DNA sequence, psychological depression being co-morbid with FM and how depression is associated with pain, and social life stressors such as stress in the workplace. Discussed the African Americans general health related issues, African American males' health and medical care in understanding those health issues related to African Americans in general and African American males. In the majority of the research literature, subjects were females with a few studies with Caucasian males, Hispanic males, and African American females (Schaefer, 2005). A more comprehensive study is needed to demonstrate the lived experiences of African Americans males who live daily with the chronic musculoskeletal disorder of FM. Chapter 3 covers the qualitative methodology with a thorough explanation of the instruments used.

## Chapter 3: Research Method

### **Introduction**

The purpose of the present study was to examine the lived experiences of African American males with FM in order to understand how the illness had affected their quality of life. Little is known about how African American males access healthcare information and use of the internet to find out information about the pain they experience. In this chapter, I introduce the qualitative design of the research study, the rationale for selecting this design, and how I used the qualitative research design to address the primary research questions. I also discuss the setting for this study, the target population, and the procedures I used to recruit participants. Finally, I discuss the role of the researcher, issues of trustworthiness, and the ethical procedures I used throughout the study.

### **Setting**

I recruited subjects through churches and barbershops in the Houston, Texas community. The inclusion criteria for the targeted participant pool included the following: the participant must be an African American male over the age of 18 years, the participant must have been diagnosed with FM by a physician and had FM for no less than 90 days, and the participant must be their own legal guardian and able to consent to participate.

The research was voluntary, and the participants could drop out of the study at any time (Creswell, 2009). I conducted the interviews by telephone during scheduled sessions. During telephone meetings, I asked open-ended questions and recorded participants' answers to the questions (Creswell, 2009). Descriptive field notes were

used, which included detailed descriptions of nonverbal communication such as the tone of voice and any longer than usual pauses during the interview.

### **Research Design and Rationale**

RQ1: What are the lived experiences of African American males diagnosed with FM?

RQ2: What is the experience of African American males diagnosed with FM with the healthcare system?

RQ3: How is the internet utilized by African American males diagnosed with FM to gather information about FM?

In the current study, I worked to identify the past and present experiences African American males with FM have dealt with and the effects these experiences have in their daily living. I asked questions about African American males' everyday lives and experiences after being diagnosed with FM. I used a qualitative phenomenological design, which entailed asking questions to explore the meaning and gain information from lived experience of African American males with FM (Creswell, 2009). I selected this qualitative design because it was best suited to describing the way in which African American males with FM understood their illness and expressed how FM has changed their lives.

Qualitative research was the appropriate research design for this study because this study related to understanding aspects of participants' social lives and lived experiences, and the method can be used to collect rich verbal data (Creswell, 2009). I did not use a quantitative or mixed method design because of the desire to identify and

explore the lived experiences from a phenomenological view of African American males with FM. Quantitative or mixed methods usually measure multiple variables against one another (Creswell, 2009). In the present study, I was not measuring variables but rather exploring the features of everyday life, the understandings, and experiences of African American males with FM (Creswell, 2009).

### **Role of the Researcher**

My role as the researcher was as an objective observer. I provided participants an explanation of my role as the researcher and not as a member of the group (Greenbank, 2003). Biases, assumptions, expectations, experiences, and any conflict of interest were discussed with the research participants, as well as, how I am qualified to conduct my research (Greenbank, 2003). So that other researchers can successfully replicate this study, I reinforced the research by making attempts to eliminate barriers (Creswell, 2009). To ensure that correct information was received from the study participants and is a reflection of the participants' views, I used a semi-structured interview as the primary data collection method (Creswell, 2009). All telephone interviews were digitally recorded.

### **Qualitative Methodology**

I used a descriptive phenomenological method for this study. I selected this method because it enabled me to maintain the viewpoint of the participants in the study (Giorgi, 2009). The method required that I (a) keep a focus on the phenomenon of FM, (b) investigate the participants' types of lived experiences, and (c) identify what information can be learned as well as how these experiences have changed the quality of

life (Giorgi, 2009). Creswell (2009) emphasized that the phenomenological method is based on the experiences of participants. I focused on the participants' external and internal experiences including their memories, meanings attributed to the experiences, and images associated with the past events.

### **Population and Sampling Procedures**

The target population for this study was adult African American males who had a diagnosis of FM. I used a convenience sampling strategy to recruit participants (Mack, Woodson, MacQueen, Guest, & Namey, 2011). Specifically, I targeted the adult population and participants who were their own guardians; therefore, the age range of participants was 18 years and above.

I obtained a convenience sample of approximately eight African American males with FM by placing notices at churches and barbershops in the community. The selection criteria made the findings of this study not generalizable to individuals of any other ethnicities, females, and minors. I continued the interview process until no additional information emerged, which is known as saturation (Creswell, 2009).

### **Inclusion and Exclusion Criteria**

I developed a set of inclusion and exclusion criteria to determine who was eligible to participate in this study. To be included in the study, participants must have been African American males over the age of 18 who had been diagnosed with FM and who did not have a legal guardian. They also were required to have a minimum of a high school diploma, and to be able to read, write, speak, and comprehend English. To be excluded from the study, participants were other than African American males, under the

age of 18 and did not have a diagnosis of FM, and had a legal guardian and did not have a high school diploma and unable to read, write, speak, and comprehend English.

If any of the participants met any of the exclusion criteria, then they were considered as not eligible for this study. All study participants had to meet all eight inclusion criteria to be considered eligible to participate in this research. Inclusion criteria were assessed by self report.

I used the inclusion and exclusion criteria to identify the eight African American males with FM. Notifications of this study (Appendix D) were made public on community churches' and barbershops' bulletin boards as noted in. The notification for informed the public of the purpose of the research, identified me as the researcher who was performing this study, and included a phone number for potential participant to call.

Several prospective participants called me to discuss their interest in participating in this study, and I selected a final sample of eight participants. If the study had not achieved saturation with the eight participants, then I would have continued sampling and analyzing data until there was no evidence of new information (Creswell, 2009); however, this was not necessary.

### **Instrumentation**

I used open-ended semi-structured interviews to collect the qualitative data; the interviews comprised 10 questions (Appendix C). I developed an interview instrument to gather lived experiences of African American males. An expert panel reviewed the interview instrument for consistency with the research questions.

The interview questions related back to the three research questions in the areas of (a) the lived experiences of African American males with FM, (b) their experience with the healthcare system, and (c) how they used the internet. I reviewed Toye et al.'s (2013) qualitative research on FM and Olle, Jennifer, Gunner, Per, and Bengt's (1999) qualitative research on FM to help develop the interview instrument for this study. Participation consisted of one 30-50 minute interview. If the participant was unable to complete the questions on the interview instrument, a second scheduled appointment was made to complete the remaining questions on the interview instrument. I began the interview with the opening question about what it is like to live with FM (Olle et al., 1999). The participants was encouraged to share past happenings where they may have felt most anxious and experienced a greater impact while providing a description of living with FM (Olle et al., 1999).

### **Procedures for Pilot Study**

I piloted the interview instrument with two participants from a community church in Houston, Texas and who had prior knowledge of FM. The pilot participants were males and had to meet the inclusion criteria for this study. There was no compensation for this pilot study. The pilot study helped check for any ambiguities in the questions and if the participants had suggestions about the interview instrument (Loh, 2013). I used the pilot study participants' suggestions regarding the questions on the interview instrument to make revisions to the questions on the interview instrument. I digitally recorded and transcribed the pilot study participants' responses to the questions on the interview



instrument. I sent the digital recordings and transcriptions to the chair of this dissertation to review the recordings and transcriptions for feedback.

The pilot participants went through an exit process that included debriefing and I restated the purpose of the research and answered any questions the pilot participants had (Anney, 2014). I took all precautions to identify and decrease any possibility of any harm to the pilot participants by providing the referral telephone numbers to the Suicide Prevention Lifeline and the National Institute on Mental Health in an email I sent to each pilot participant.

I coded the transcripts from the interview with a numerical coding system assigned to specific themes. For the cases that were discrepant, I looked for what each case has in common with the other situations (Shenton, 2004). The interview instrument was piloted to determine whether there were any specific issues where changes to the open-ended interview questions were necessary. I kept a descriptive diary to document pilot participants verbal and nonverbal cues and any biases I had during the interview (Anney, 2014).

### **Procedures for Recruitment, Participation, and Data Collection**

The participants was selected based on their experience of being African American male with FM. The data was collected using the interview instrument and the responses of the recruited participants through the FM social media websites (Englander, 2012). They were compensated with a \$10.00 Starbucks Gift Card as a thank you for participating in this study. The interviews lasted approximately one hour. All of the data was digitally recorded and uploaded daily for security and confidentiality (Winer, 2012).

### **Qualitative Data Analysis Plan**

The participants' responses to the open-ended questions on the interview instrument were digitally recorded and transcribed. I analyzed the transcriptions using Karlsson's (1993) empirical phenomenological psychological method. The method included the following steps for analyzing the transcriptions (a) read the transcriptions individually to obtain a proper understanding of the content, (b) each transcription was separated categorically, (c) each category in each transcription was converted into the researcher language, and (d) each converted category was changed into themes; and (e) to make the themes understandable, any quotations that seem to be significant accompanied each theme (Karlsson, 1993).

### **Issues of Trustworthiness**

#### **Trustworthiness**

I achieved trustworthiness through credibility which was gained by establishing the results of the research participants' actual experiences (Flyvbjerg, 2011). The same interview questions were asked to each pilot study participant to bring about triangulation (Flyvbjerg, 2011).

#### **Credibility**

To gain credibility (a) I digitally recorded the pilot participants' responses to the interview instrument, (b) I transcribed the digital recordings, and (c) I sent the digital recordings and transcriptions to the chair of this dissertation to critique how the open-ended interview questions were presented and the interaction between the researcher and

pilot participants. This process helped to decrease the chances of unanticipated problems (Anney, 2014).

### **Transferability**

I achieved transferability by (a) providing information about me, (b) provide the background or framework for the research and demonstrate the steps taken to conduct the research, and finally, (c) the relationship between the researcher and participant was examined to determine if any findings were transferable (Morrow, 2005). The study could be possibly generalized to African American males with chronic pain, but this is yet to be seen.

### **Dependability**

I established dependability by creating audit trails to maintain an accurate record of all the events that occurred in this study, such as who I met with and what was discussed (Anney, 2014). Themes from the responses to the interview questions from the African American males with FM, conclusions and interpretations were made according to the answers provided to the research questions and biopsychosocial theory. Recommendations resulted from the findings and were supported by sources.

### **Confirmability**

I established confirmability by developing a short audit trail whereby an external researcher tracked the events to determine the findings, interpretations, and recommendations of this study (Lincoln & Guba, 1985). Records that were part of the audit trail were (a) raw data such as diary notes and digital audio sessions, and (b) interview instrument. My biases were made known to maintain confirmability.

### **Intra and Intercoder Reliability**

I used the strategy of crosschecking of coding and interpretation of data by having another person look at the data and review for any or all emerging coding themes (Flyvbjerg, 2011). A Walden University doctoral student assisted as a second coder. The second coder had no prior knowledge of this research aims and objectives and thereby helped to reach reliability in the cases being used for the analysis (Flyvbjerg, 2011). The second coder completed a confidentiality agreement.

### **Ethical Procedures**

#### **Agreements**

Prior to posting flyers in the Houston, Texas community, I asked four FM group forum website coordinators to post an ad to recruit African American males with FM who were active FM group forum members. The identified four FM group forum websites were (a) African American FM Foundation Support Group, (b) Fibro Support for Men, (c) Men with Fibro Online Support Group, and (d) Men with FM, Not Just a Little Thing – FM Forum and Support Group. The purpose of the request to post an ad was to obtain access to the population needed for this study.

#### **Treatment of Human Participants**

The participants were recruited from an ad posted in the Houston, Texas community. The information included the name of the researcher, the study name, and the purpose for the research. A contact telephone number was provided for eligible participants to communicate with me about this research. For safety purposes, a dedicated cellular number was used for this study.

The informed consent form for the main study, included in Appendix E, was in an email that I sent out to each participant. The consent form was fully explained to ensure all participants were aware of their rights as a volunteer member. These rights included (a) the right to refuse to participate at any time during the study without reason, (b) the right to understand how confidentiality will be maintained, and (c) the right to know how the data will be used (Corti, Day, & Backhouse, 2000).

### **Treatment of Data**

All participant information was kept confidential (Corti et al., 2000). Confidentiality was maintained through removing primary identifiable information such as names, and addresses from emails and demographic form. The data was preserved for future research and removal of identified details was cautiously strategized by appropriately assigning pseudonyms (Corti et al., 2000). Gate-keeping for the data information was restricted and only available to the dissertation chair, committee members, and me as the researcher (Corti et al., 2000).

Ethical considerations were given to how the data is protected. All data I kept in a password protected flash drive with limited access (Corti et al., 2000). After 7 years, all data will be destroyed in accordance with requirements from the American Psychological Association (2010). All digital audio recordings were protected by placing information on a Universal Serial Bus (USB) and uploading the files to a drop box for secure confidential storage (Winer, 2012).

### **Threats to Validity**

To minimize threats to validity, I piloted the interview instrument, and feedback from the pilot participants was used to make necessary changes to the instrument to demonstrate validity. The chair of this dissertation and an expert panel reviewed the interview instrument, pilot study responses to the interview tool, and all suggestions that the pilot participants gave about the interview instrument.

### **Summary**

This chapter focused on the research design and rationale for conducting this study. A phenomenological qualitative methodology approach was used to retrieve information about the lived experiences of African American males with FM. The chapter provided a description of the select population, steps taken for data collection, and outlined a data analysis plan for this research. Lastly, the ethical emphasis was on reviewing the treatment of human subjects, as well as considering any threats to validity.

In Chapter 4, the section stating the results, I included the data analysis that responds to the research questions and hypothesis. A table in Chapter 4 assists in clarifying the findings of this study.

## Chapter 4: Results

### **Introduction**

There is little information about the lived experiences of African American males with FM and how this illness has affected their quality of life. My aim was to examine the lived experiences of African American males with FM and their opinions about the healthcare system, healthcare providers, and internet use. I used a descriptive phenomenology psychological study method, which afforded the opportunity to examine each participant's experiences in their entirety while maintaining the participants' viewpoints (Giorgi, 2009). The individual interviews were guided by three research questions that I developed and used to gather the required data. Chapter 4 includes a detailed description of the pilot study, the setting, and participants' demographic information. The chapter also includes an overview of the data collection and data analysis procedures, evidence trustworthiness, and the interview results. I conclude Chapter 4 with a summary.

### **Pilot Study**

I conducted the pilot study with two males from a Houston, Texas community church who had prior knowledge of FM. Both participants met the study's age requirement ( $\geq 18$  years) and had a chronic pain disease diagnosis. I emailed both participants the pilot study consent form, and a copy of the interview instrument (Appendix C). The pilot study participants were provided a verbal and written detailed description of the research study and the steps I would take to conduct the interview. Both participants gave consent. The pilot study interviews were conducted over the

telephone and recorded. I asked each pilot study participant to respond to the same 10 interview questions developed for the main study. At the end of each interview, I asked the pilot study participants to provide feedback about the clarity, structure, appropriateness, and relevance of each question. From their responses, I determined that all of the 10 interview questions were easy to understand, appropriate and relevant to the research topic, and that participants did not feel distressed after the completion of the interview.

I transcribed and typed the two pilot participants' recorded interviews and completed the second review for accuracy and completeness. After the completion and thorough review of the two interview transcripts, I encrypted the transcripts and emailed to my dissertation chair, Dr. Leann Stadlander, to review the accuracy of the typed transcripts. After Dr. Stadlander's review, we both agreed that the 10 interview questions were appropriate for this study.

### **Setting**

I conducted seven of the interviews by telephone, and one face to face. The one participant preferred to conduct the interview face to face in a safe, confidential public location.

### **Demographics**

The study had a total of eight male participants who met all eligibility criteria. All eight participants were African American and had a diagnosis of FM. The participants ranged in age from 56 to 69, and had an average age of 64. Table 1 displays the demographic information for each participant.



Table 1

*Main Study Demographics*

Participant	Age	Marital Status	Education	Veteran
John	66	Married	PhD	Yes
William	65	Single	GED	No
Barry	60	Married	PhD	Yes
Raymond	56	Single	GED	No
Geoffrey	69	Widow	MA	Yes
Colin	68	Single	GED	No
Bruce	63	Divorce	MA	Yes
Keith	65	Married	MA	Yes

*Note.* ( $N = 8$ ). Participant's names are pseudonyms.

### **Data Collection**

The study began after receiving Walden University IRB approval #03-09-17-0165753 in March 2017, and I completed data collection in August 2017. I encountered problems recruiting participants, and therefore made three separate requests for a change in procedure to the Walden University's IRB. The first request was to change the format of the research flyer to recruit participants and post on social media such as LinkedIn and Facebook. The second request was to give each participant a \$10.00 Starbucks gift card for participating in the study and to post my picture on the research flyer to show that I was an African American researcher in order increase the number of African Americans recruited. Permission was granted. Due to problems encountered with the Walden

University Office 365 Outlook, the third request was to add my private email address to the research ad (Appendix F) and consent form.

Participants communicated with me by email or phone to provide consent and to schedule times for the interviews. The interviews were conducted by telephone for seven participants, and one participant preferred to be interviewed face to face in a confidential public business. At the beginning of the interview, I offered a verbal “thank you” to participants for taking time out of their schedules to participate in the study. I emphasized to all participants that confidentiality would be protected.

All eight of the study participants were screened for the study’s age, education, guardian status, and FM diagnosis criteria. The participants were informed that the interview would be recorded, and they voluntarily agreed to be interviewed and recorded using a digital recorder. I conducted seven telephone interview recordings from my private home office, and the location of each participant was unknown. One participant’s interview was conducted in a public business. I asked each participant if they were in a setting that was safe, private, and comfortable. All eight participants confirmed their environment was safe, private, and comfortable for the interview. I provided a detailed description of the purpose of the study and explained the steps I would take to carry out the interview. I also emphasized that their responses would be stored in a locked file cabinet. Each participant was informed their real name would not be used during the recorded interview and they would be assigned a pseudonym to ensure confidentiality. The participants went through a debriefing process at the end of the interview to decrease the probability of any stress or harm (Anney, 2014).

At the beginning of each interview, I collected demographic information including the participant's age, highest level of education, and state of residence. The interview instrument consisted of 10 open-ended questions that I asked each participant in a sequential order. I digitally recorded all eight interviews, and the participants answered the 10 interview questions within 45 to 75 minutes. The interview duration was based on the amount of detailed information each participant provided. A detailed diary with notes was kept for each interview, and I used the notes as cues to follow-up with additional questions and clarifications. Multiple prompts and follow-up questions were asked to address the research questions and to collect further data regarding participants' lived experiences with FM. All interviews were completed in their entirety the first time by all eight participants.

At the end of each interview, I electronically saved and coded the digital recording file. I transcribed and typed each digital recording and reviewed each multiple times for accuracy and completeness. The hard copies of the hand written transcripts, typed transcripts, and the hand written diary notes have been stored in a locked file cabinet. The electronic files such as audio recordings, transcriptions, and spreadsheets, are stored on a USB drive in an envelope marked "Confidential" and placed in my personal locked file cabinet. I am the only person with access to the key to the file cabinet (Corti et al., 2000).

### **Data Analysis**

I used a descriptive phenomenological method for this study, and I kept the emphasis on the phenomenon of FM and the various types of lived experiences identified

by each participant (Giorgi, 2009). I was also able to identify what information can be learned and how each of the experiences shared had changed the participants' quality of life (Giorgi, 2009).

For data analysis, I used the eight typed interview transcripts, which were then typed into a Microsoft Word table. Each interview response to the 10 questions was read multiple times to formulate codes, emergent themes, and sub-themes (Karlsson, 1993). The table assisted in methodically developing codes one at a time. I developed a legend for each question to explain what the symbols and colors represent; the legend also included a listing of each emergent theme and codes for the 10 interview questions.

To formulate the codes, I extracted partial comments from the eight participants' responses to the 10 interview questions and placed them in a single cell in a Microsoft Word table. The partial comments associated with each interview question were typed in red, and from these specific comments, the codes emerged. At the beginning of each typed red partial comment, a green highlighted capital letter 'C' in parenthesis was the identifier for that specific code. The codes were numbered as a way to identify each code, and the numbering of the codes started with 'C1' which was recognized as Code 1. The diary notes captured the emotions and feelings identified during the interview for each participant. Each interview question included diary notes, which I placed on the table and highlighted in yellow as an identifier. The yellow highlighted diary note would follow the partial comment surrounded by enclosed parenthesis and were included in the coding formulation.

I used a second Microsoft Word table for sorting data that was collected from the codes. The sorted data was then placed in single cells that corresponded with each participant and the 10 interview questions. The interpretation of these codes included finding theme frequencies, identifying theme co-occurrences, and word searches to identify and analyze the meaning of participants' interview statements (Karlsson, 1993). From this process, I performed a thematic analysis to obtain the emergent themes by reading and re-reading the identified codes for each of the 10 interview questions. Validation for commonality between the three research questions was conducted, and a careful analysis showed six common themes associated with the three research questions. For example, three themes (lengthy diagnostic, physical limitations, and negative coping and denial) emerged in answers to RQ 1. Finally, themes for RQ 2 were associated with themes that I had identified in RQ 1 (e.g., physical issues, limitations, trust, and denial), thereby showing the relationships among the emergent themes. To determine an in-depth meaning of the themes, I referenced them to the constructs of the biopsychosocial theoretical model (Engel, 1977). In the Results section, I present the results, the themes developed along with the support of the participants statements, and any detailed variances.

### **Triangulation**

I achieved triangulation by asking each participant the same interview questions (Flyvbjerg, 2011). I developed multiple Microsoft Word tables to sort the data and to find the themes and the most common themes. The identified common themes were connected to the participants' responses about the topic. The responses were examined

and reviewed for likeness and dissimilarities. This method of data triangulation cautioned the researcher of any bias. The validity of themes was established from the sorting of themes for commonality.

### **Evidence of Trustworthiness**

The qualitative criteria used to determine the trustworthiness of the interview results were credibility, transferability, dependability, and confirmability (Shenton, 2004). This section presents the steps taken to demonstrate the evidence of trustworthiness. Ensuring that I gave an accurate account of the experiences that were shared and made sure the study had reached saturation created credibility for this study. I further established credibility for this study by keeping a diary with observations and asking additional follow up questions to gain clarity to the interview questions that were digitally recorded and transcribed.

I addressed transferability in this study by providing a thick description of the eight participants' experiences (Creswell, 2009). Although there was a problem in obtaining responses to the posted research ad placed on the FM websites, I then requested Walden IRB approval to recruit participants from social media such as LinkedIn, Facebook, and in the community. The participants represented were all African American males with a diagnosis of FM, over the age of 55, and varying education levels from a General Education Degree (G.E.D.) to a Doctorate of Philosophy (Ph.D.). This study results could apply to other African American males with similar chronic pain diagnosis. The study demonstrated dependability and confirmability by providing audit trails of the detailed record of events that occurred and thereby providing enough

accurate information for another researcher to assess if the results can be applied in a different setting (Anney, 2014). I used a second coder who was a Walden University Health Psychology Doctoral Candidate to review the data for emerging themes and thereby to demonstrate the reliability of the data analysis (Flyvbjerg, 2011).

### **Results**

The study findings are presented in this following section where I address the three research questions:

RQ1: What are the lived experiences of African American males diagnosed with FM?

RQ2: What is the experience of African American males diagnosed with FM with the healthcare system?

RQ3: How do African American males diagnosed with FM utilize the internet?

The data was collected from eight African American male interviewees that were 56 years and older. In this section, there are six emergent themes that I present, along with examples of the participants supporting and non-supporting views. The anonymity of the participants, as well as the names associated with the quotes, are protected with pseudonyms. The research questions were created to identify the past and present experiences, and the effect these experiences had on the participants' daily living. All interviews were conducted in a confidential private setting, and the participant's consent was acquired before the interview. The interview instrument created for this study can be viewed in Appendix C. The interview instrument consisted of 10 interview questions that

addressed the three research questions. Each participant's response was thoroughly coded to show the relevant information.

The interview responses to question 1 addressed how the participants were diagnosed with FM, and interview responses to question 2 addressed what were the participant's experiences since being diagnosed with FM. The interview responses to question 3 addressed how family and friends reacted to the participant's diagnosis of FM. The interview responses to question 4 addressed the participant's job, and any effects due to FM, and interview responses to question 5 addressed how the participants felt about their current situation related to work. The first five Interview Questions 1, 2, 3, 4, and 5 addressed RQ 1. The interview responses to question 6 addressed the participants experience with the healthcare providers since being diagnosed with FM, and interview responses to question 7 addressed how the participants obtained medical information from their healthcare providers on FM. Both Interview Questions 6 and 7 addressed RQ 2. The interview responses to question 8 addressed how the participants go about using the internet after being diagnosed with FM, and interview responses to question 9 addressed in what way the participants felt the FM websites were helpful. And interview responses to question 10 addressed how often the participants used the FM support groups or forums. These last three Interview Questions 8, 9, and 10 addressed RQ 3.

**RQ1.** The first research question was: What are the lived experiences of African American males diagnosed with FM? I present the four themes that emerged from participants' responses about how they were diagnosed with FM.



## **Theme One**

The first theme that emerged for RQ1 was: “There were lengthy multiple medical evaluations to receive a diagnosis and various symptoms.” The participants described the length of time it took to get diagnosed, the symptoms they experienced, and the medications they were prescribed to treat FM. The one response that was common among eight participants was that FM was very debilitating at the time they received their FM diagnosis and were all prescribed various types of medication to help decrease the pain and symptoms that were caused by FM. Excerpts from the participants’ responses that support this theme are presented below.

**Diagnostic duration.** The most common reply for the seven of the eight participants was that it took months to years before they were given an FM diagnosis. One participant, Barry (60-year-old male), noted, “Well, I think it might have begun in 04...And I think I didn’t get a diagnosis until about 09, 09 and 5 years after, I think.” Bruce (63-year-old male) commented, “It took close to 6 months going back and forth...diagnosed about 7 years ago...it was about I would say 2006.” Keith (65-year-old male) stated, “It took just a couple of doctor visits and she gave me a diagnosis.” There was one participant, William (65-year-old male), who stated “not sure” when he received an FM diagnosis. Although I gave multiple prompts to try to obtain an approximate date for the FM diagnosis, participant William was not able to remember.

**Medical Tests.** All eight participants provided a common response to the interview question in having diagnostic testing performed to get an FM diagnosis. John (66-year-old male) reported: “I go to the VA Hospital, and there were tests...x-rays, lab

work and physical examination performed there.” William (65-year-old male) commented: “Had x-rays and couple physical examinations.” Barry (60-year-old male) stated: “Yes, they did all kind of things, images, physical exams to everything, all kind of things to me.” Six of the eight participants reported they all had diagnostic imaging performed as part of the FM diagnostic process. Only five of the eight participants received lab work from healthcare providers to diagnose FM. Out of eight participants interviewed, only two participants stated they had a physical examination from their doctors to obtain an FM diagnosis. I observed that one of the eight participants Keith (65-year-old male), was the only participant who reported only having one diagnostic test performed (e.g., lab work) from a healthcare provider, to obtain a diagnosis of FM.

**Symptoms.** From the responses of the eight participants, the most common answer was they all had pain as a symptom of FM, the symptoms were debilitating, and they all were taking medication for FM. One participant John (66-year-old male) commented: “And it felt like the cutting of a razor blade. I couldn’t rest on my left side because of that...yes, debilitating and yes, it’s embarrassing sometimes too. Ibuprofen 800 for the overall body pain (take this medication).” Barry (60-year-old male) stated:

I was constantly having pain everywhere and then I was finally referred to a pain clinic at the VA Hospital, I’m a veteran. I was in awful terrible pain. I mean pain everywhere. If you touch my body like touch my hand my entire body kept having pain. Well, I be honest with you, I was taking Lyrica...had side effects.

Raymond (56-year-old male) reported:

Had overall body pain and aching especially in both legs they hurt real bad. Oh yes ma'am I have trouble walking around. I must use a walker to assist me.

Well, my doctor gave me some pain pills and muscle relaxers.

Five of the eight participants mentioned experiencing anxiety. Geoffrey (69-year-old male) stated: "I didn't want to admit that this was happening and though it would probably go away...oh it's a road to anxiety (sounded hopeless)." Colin (68-year-old male) noted: "A lot of times they keep me agitated." Keith (65-year-old male) commented: "Uh, yeah, at times I'm sure I have, I'm sure when you can't move around as comfortably as you would like uh, when you're debilitated at certain periods of time causes anxiety hmm hmm (sounded sad)." Several participants mentioned they had other symptoms such as numbness, tingling, headaches, problems sleeping, cognitive challenges, problems getting around, depression, and sensitivity.

## **Theme Two**

The second theme that emerged for RQ1 was: "There were physical challenges, physical limitations, emotional issues, cognitive issues, efforts, and the effects of FM at work." The participants shared their physical limitations, problems, emotional, and cognitive issues that they had experienced with FM and the efforts they used with FM.

**Physical Challenges.** From the responses of seven of the eight participants, the most common reply they made was experiencing some ambulatory issues. One participant John (66-year-old male) reported: "At times, I have to hold myself together to keep from you know stumbling (sounded sad). But now I have to make sure I'm holding

onto the rails and sometimes that's embarrassing (sounded embarrassed, shame and sad)."

William (65-year-old male) commented:

I get dizzy while I take a walk now like lightheaded. Nah, I, no, I can't walk long distances. I have to stop and lean up against something. So I lean against something for about 5 minutes and then I take off again until I get back to the house. I just walked to the store and it took me almost 45 minutes to walk back and it's only 10 minutes from here (sounded down and sad). Takes real long time to walk.

Raymond (56-year-old male) stated: "When I sit down at the dinner table for a while, I have to have somebody to help me get up so I can walk on my walker (sounded sad)."

Bruce (63-year-old male) commented: "I use, most of about 80 percent of the time with a cane...I was using a cane and would be paining in the knee and shoulder."

Keith (65-year-old male) reported: "No, I don't use a cane I use a walking stick when I walk."

Although one participant did not have a cane, Colin (68-year-old male) noted: "No ma'am I need one (referencing a cane)."

**Physical Limitations.** The most common reply for the eight participants was they were limited in activities, felt like an old person, and accepted or did not accept assistant walking devices. The participant John (66-year-old male) commented:

You know it's really kind of disgusting for me as a young person, young man, even as a teenager I could walk up and run (said with emphasis and proudly) up and downstairs. Because I cannot do what you say like the average person, like

stairs, trying to get on an escalator going upstairs (sounded down). Second floor have a shorter area and I have to make sure I hold on, and I step on right and I'm looking down like an old person (said with emphasis and sounded upset)... but I need that aid, that assistance, that aid to help me to get from point A to point B (sounded embarrass and upset). No, I'm 90 percent disabled. On my license plate I have a...disabled veteran, but yes again I don't have the wheelchair on my license plate (felt proud he didn't have a wheelchair logo on his license plate).

Another example is participant Barry (60-year-old male) who noted:

You feel like a teenager and you're in an old body. Everywhere is hurting. You will never catch me with anything on my shoulder because to me to put too many things on my shoulder I tend to hurt more. Even holding things in my hand will hurt and ache. In fact, a challenge waiting in line for security (in reference to the airport) yeah it was. Yes, ma'am I do have a VA handicap plate. Yes, I use it most times and even then...but sometimes I try to leave it there for someone more handicapped than I am (laughter). But if I see a spot nearby I will use the spot but then it doesn't matter if I feel guilty. I should use it (laughter).

Keith (65-year-old male) commented:

I don't do any formalized exercising except uh yard work (sounded frustrated). I mean I consider my yard work and then over the years I (pause) I tried to walk and do some walking but not enough of that but basically, I kind of just regulated to yard work and so forth around the house. I did extensive yard work last week and I had new pains that I never experienced before...just indescribable kinds of

muscular joint pain on a specific side. Because you know it was my normal routine except that was a little bit more a little more longer in duration. I found myself having to do a lot more so maybe that was the cause of this change, I (pause) the over exertion perhaps. Yes, I am a (a veteran)... biggest concern and need is you know...I asked in just the last 6 months or so for a placard for parking...guy gives me a temporary one but this I tell them hey this been going on for years you know (sounded angry).

**Emotional Issues.** The most common response for four of the eight participants was that they had experienced embarrassment, negative feelings, pride, medication apprehension, and depression. The participant John (66-year-old male) reported:

Even going to the airport getting on the escalator you know it's embarrassing (stated loud and with emphasis). That may be pride (laughter). I say I don't want to give in to any physical aid. Maybe that's part of my upbringing. Even though I am 66 I don't want to give in to that, even though a doctor at the VA said it's nothing wrong walking around with a cane. But no (said with emphasis and adamant). As a matter of fact, last year, year before last I was at the gas station going in to pay for my gas and I stumble and fell...It was early in the morning, I was coming back to my business here, it was the clerk and another person out getting gas and they...and they just stood there and looked at me (sounded sad and embarrassed). I fell flat on my left shoulder. Nobody (said with emphasis), they just stood there looking at me but maybe they thought I was...I don't know what they were thinking. It was a concerned for me for sure but they... (Sounded

hurt feelings). I'm sort of...edgy uh, uh...in that, this, uh, like I'm going to stumble, and it come sort of unexpectedly and I don't know when it's going to happen. So, it makes me very kind of uptight so to speak.

William (65-year-old male) noted:

So, you have to stand up for that long on the bus ride and I sit on the steps sometimes and you know people have to ask me to get up and let them by when they getting off at their stop, that makes me feel kinda bad and embarrassed.

Don't want no narcotic, Norco the doctor tried to prescribe, because you can get addicted to it, said no (stated with emphasis).

Geoffrey (69-year-old male) stated:

I go out alone...into the store without a list and uh left without half the things I went for, so that had me thinking like that. It doesn't happen often but when it does I'm really frustrated and uh almost angry with myself (sounded upset). I have to recall. I'm taking Gabapentin 300 mg...I'm supposed to take one tablet in the evening...messes with my cognition...I'm a quick thinker...it slows me down (laughter). My God give me wisdom and the wisdom part is I know this medication is going to impair then I don't touch it.

Colin (68-year-old male) reported: "Depressed from that...all the time." "It makes it hard for anyone to get along with me (referencing when he is in pain)." Keith (65-year-old male) stated: "No, no, I'm one you know that don't like medications per se you know period (stated with emphasis)."

**Cognitive Issues.** The most common answer for five of the eight participants was they seemed to experience forgetfulness. The participant Geoffrey (69-year-old male) stated:

The only thing that really shocked me, uh, summer before last when I went to get my driver's license and the woman who was the clerk ask me what's your number...I couldn't think of it. I was so embarrassed (sounded embarrassed). I've been knowing this since I was 16 (a little laughter with embarrassment). I was shocked, yes always know it and I couldn't think so, I had to go into my wallet and pull it out. What got my attention this never had anything like this to happen before...called Alzheimer Hotline get some counsel...had tests for that...but so far negative.

Barry (60-year-old male) mentioned:

I have a lot of that hmm hmm...fogginess in the mind. Oh my God yes, let me tell you I prefer a dark area. I am sensitive to everything. I guess.

Bruce (63-year-old male) mentioned:

Yeah, I do forget where things are. I've even left home and forgotten wallet and keys and it's pretty regular to maybe once every one to two week period I leave without my wallet and I usually have it all together.

Keith (65-year-old male) commented:

Uh sound, I seem like to have a little more sensitivity to noise yeah. Like TV volume and so forth. Like I probably do, I can't really quantify that I can't really basically focus on it and the problem. But uh, but I use to, I pride myself on my



recall. Recalling a fact and that's uh, a little more uh, it's lessen uh, quite a bit as I as...it's happened, it's happened, not, not knowing be yeah, yeah. Uh, umm (pause 4 seconds) I have you know, I can a couple you know would go away and kind of forget you know, you know. Yeah, usually I try to focus on where I parking my vehicle. Kind of enough said.

**Efforts.** The most common answer for six of the eight participants was coping and avoidance as an effort in dealing with the challenges of FM. As an example, participant John (66-year-old male) commented:

Yes, I do the same challenges and I just deal with it. And there are times I have to ask for assistance in helping me. I have to ask for help at times and its ok (hesitated), but again it's just part of life (sadness) and I have to deal with it (sad). I don't really...what I'm really trying to say I'm not ready to sit down. Well, it makes me feel like, yes, I'm handicapped and I'm not able to take care of myself (sad and feeling unworthy).

Barry (60-year-old male) reported:

I would always try to avoid people because what happens everybody want to hug you and shake your hand (referencing church members) and I didn't like no one touching me (said with emphasis) and I was tired of telling people I can't go through you shake my hand. These were peoples that socially shaking hands. I remember this guy one time actually cursed out because I said don't touch me.

Geoffrey (69-year-old male) commented:

I just tough it out...I've had to had this experience for 4 or 5 days before I'll take the pill. Because I don't want that indifference, because if I have something coming up or something that's going to require my thinking abilities to kick in and creativity now, I just tough it out.

Colin (68-year-old male) stated: "Uh, I try to cope with it or deal with it. The pain is so great at times I just get depressed a bit." Bruce (63-year-old male) reported: "Yes, definitely, definitely cope with pain (stated with emphasis)." Keith (65-year-old male) noted: "I've conditioned myself to just push through it (persevere coping tone)...but yeah I would kind of say uh it's always there (laughter)."

Theme two also addressed the challenges and the effects of FM at the participants work. There were five participants that shared the effects FM had on their job.

**Effects of FM at Work.** Five of the eight participants had the common answer of FM symptoms affecting while at work. The participant John (66-year-old male) commented:

As the owner Director of a Personal Care Home, in my...doing my chores and responsibilities around here it does affect me sometimes. Some...but as a whole I'm fine but sometimes...some days I am really uh...I just stagger sometimes, and my clients are concerned, what's going on, what's wrong, so from time to time it does affect me sometimes, but they know it by now (sounded sad). Sometimes, sometimes, yes especially as a Minister going to church, going to the pulpit going to the stairs I had problems there. In walking up or down...up or down the stairs. And then even at funerals making your exit out of church, I'm challenged. There

may be a little uh...dizziness uh...there. After I would get up to stand it would be ok, but in the process of...between the seat...your seat and the pulpit area, the next turn there would be some challenges there. I don't know when this is going to happen but I'm challenged like that. Suck it up and go on, do what you got to do (laughter), remember I was in the military. I do what I need to do. I'm a fighter (said proudly).

Barry (60-year-old male) mentioned:

Well, uh, like I said with my job I'm an Administrator and I'm the Research Coordinator. So, I do a lot of tracking in clinics and a lot of recruiting so I walk all over that place. And at the end of the three to four hours I'm in pain. So, I have to sit down and I try to isolate myself...I noticed when I go to all the other buildings what I find to be helpful I need to get new shoes as often as I can. And to be honest with you even to be that way bothers me a lot sometimes all of the walking. No my manager is not aware of my diagnosis, but I know I can get whatever I need, I know. I know when I went first to work at the VA uh, it's always a parking issue at the VA Hospital. So, what I find I was having problems...I wrote the Department of Expect that gives you special parking area. And in this information to park closer to the hospital, but what annoyed me the psychologist said my supervisor has to write in a letter to let them know what's wrong with me. I told them that was stupid and don't make sense and I don't like the apology. I don't want my supervisor to know my business (said with emphasis and sounded angry). So, when I travel a lot I end up getting sick. So,

for example I just came from Dallas uh, Saturday but I intentionally took off from work today in the event I wasn't feeling good from the long drive or whatever which I'm also one about driving too long (laughter), but I know what that is. Whenever I say I'm going to travel they (staff at work) look at me and say ok, ok, hope you're fine when you get back. It happens, it happens.

Keith (65-year-old male) noted:

Uh, just uh, you know, just moving a little slower...sitting down or standing on my feet uh just general soreness. I'm a teacher...all history's geography, government, uh economics, and you're right about recall, you have to you know, and would be nice I could recall you know, a lot of those things that use to just be their but they're not their like that anymore so (sounded sad). Uh, I have, I have to use other strategies or mechanism to compensate for that. Teach High School nine through twelve...when you discuss, your discussions lead you to areas that you really hadn't plan for or for any particular lesson and so those are the frustrating moments when you would really love to have that information that quick recall you know a fact or name a specific what or whatever and then you really can't pull out that information and then you have to defer. And so, it inhibits the lesson to that extent. Hmm, hmm I would think no one could realize the extent of my limitation. I just deal with it (sound frustrated) just deal with it.

Three of the eight participants were not working due to their current health status. They gave information based off of their past work experience. For example, William (65-year-old male) reported:

I worked at the kitchen and then I worked in the laundry and then uh that's about it...they gave me a sit down job at the table and I did that for 5 to 6 years folding laundry. Yes, I had to work and a lot of the guys that worked with me they covered for me when I'm hurting.

### **Theme Three**

The third theme that emerged for RQ1 was: "There was limited physical and emotional support from family and friends that are not well informed about FM." The participants described their family and friends as being somewhat helpful and concerned, but not well informed about their illness

**Limited Physical and Emotional Support.** The common response for seven of the eight participants was their family members seemed concerned, supportive, and friends were supportive but would ask questions about their health.

Participant Barry (60-year-old male) reported:

Yes, they were understanding because...but what they actually did they were understanding they were still frustrated too because they actually followed an active dad who runs three to 12 miles a week even can't walk and that was very frustrating for my son. I can walk but I can't run like I use to. I'm able to walk. I do trot once awhile, but still painful at times. So I just walk (sounded sad). Hmm my friends I think they were understandable because they knew I was in the military and a whole bunch of stuff happened to me.

The participant Raymond (56-year-old) mentioned:

I have family here. They come over here to the house and check on me and everything, and if I need any help they will try to get it for me...they're very concerned about my health and supportive of me. They ask me if I'm still having problems with my legs and pain and everything...tell them yes and I talked to my doctor...my friends are understanding...they help me out.

Another participant, Geoffrey (69-year-old male) stated:

They were overly concerned...oh they ask me pop are you alright? Do you need me to do this or to do that? So, I thought I'll let you know. I live alone and so my sons are over here a lot...and then my daughters they'll call they'll come...and say pop you need this you need that and whatever (laughter). A lot of them really don't know (speaking about friends). Like I was leaving the choir stand uh last Sunday morning and someone said Rev you look a little slow to me (sounded embarrass). But so far as me just mentioning it I'm like this I want just come out and say a lot of things about what's going on with me. The reason is when I go to lay hands on someone or pray for someone I find that may interfere with their faith, so I don't mention it to them. I talk with other preachers a couple about some things physically. But the general congregation I don't do that.

Bruce (63-year-old male) shared:

Uh they're aware of it and very supportive...they verbally support me with it's ok don't worry that's ok you can place this...I as waking up different hours like they are getting us to or accustom to. Uh no they (adult children) will call but I always say I'm pretty well ok...they'll call every other day. Uh they (speaking about

friends) they seem to think its ok they know it's not completely normal but they don't look at it being abnormal. Yes, yes, they have (speaking about friends support), they are.

One of the eight participants noted that he lost contact with his family many years ago and is unable to locate his family and he has no family support. Another participant, Keith (65-year-old male) mentioned: "I'm probably sharing more with you that I ever shared with my family at any time...I usually don't trouble family members with that kind of stuff generally. Uh, I would say they (referencing friends), they don't really know." Three participants stated they have no supporting friends. For example, Colin (68-year-old male) noted: "I had friends...they didn't when I start hurting they left me alone (sounded sad and down)."

#### **Theme Four**

The fourth theme that emerged from RQ1 was: "They were hopeful about work, and planned to make work better in 5 years, 10 years, 20 years, and concerns about the future." Five of the eight participants expressed positive feelings about their current situation related to work and what needs to happen for them to feel good about their status related to work. There was only one participant John (66-year-old male) who gave a correct interview response to Interview Question 5 sub-question: What needs to happen for you to feel good about your situation related to work (e.g., 5 years from today, 10 years from today, and 20 years from today)? The other participants gave partial and indirect answers to the question from a personal perspective. I have included examples of these partial and indirect responses.

**Hopeful About Work.** The one common response from five of the eight participants was, they felt optimistic about their situation at work. One participant John (66-year-old male) commented:

Well, I don't look at this just as a job per se; I look at this just as an ordained ministry. I look at this...it is fulfilling to me and the illness doesn't stop me, I'll just do what I need to do. Because I'm not ready to sit down and take a rocking chair at this time.

Another participant Barry (60-year-old male) noted:

Well, I'm somewhat mostly in control what I do at work. I work, I am a manager and but still I'm able to take my break when I need exact work. When I'm at work and I don't feel the pressure of it and like that. I try not to take advantage of it. I try to be very accountable. I'm feeling good I don't feel no way. I know when I'm going to need get alone and I know when I'm going to get a flare up. I call them flare up. I know if I'm going too much or whatever of If I get excited about stuff I try to relax and uh...and just to avoid getting the flare up.

Geoffrey (69-year-old male) stated:

I'm doing good as far as that is concerned. It's causing me to be prayerful...my strength come from and I believe that God is a very present help when I'm in trouble...and He'll never let me down.

Bruce (63-year-old male) shared: "I feel like I can do minimum amount of physical work (for) a few hours...I don't think I can go eight hours or more you know...be too much."



There was one participant Keith (65-year-old male) who was not hopeful about work and expressed:

Uh, I, uh, I'm not happy, not happy. I'm not happy because I know I can be better you know I had been better and I can be better and I don't appreciate the fact knowing what I could give it.

**Plans to Make Work Better.** One of the eight participants expressed thinking about limited plans in how to make his work situation better in 5 years, 10 years, and 20 years. John (66-year-old male) mentioned:

Well, one thing it's important to stay optimistic and it's my prayer that I be able to continue. I'm trying to keep a positive attitude and mentally see myself going forward in spite of...but and more of having some support of employees working with me (referencing 5 years from today). Well, 10 years from today Lord I'll be about 76-years-old (laugh). Hopefully I don't have to have such-a-hands on responsibilities of running this place. Oh, how old I'll be...86 (laughter). Are you going to be here (humor with laugh)? And 20 years from today, so hopefully at this time I don't even have to even be here and they report to me and say it's going fine and hey, I can go on a cruise and just enjoy myself. So, hopefully I really want have to be around here and yet the ministry will go on.

Five of the eight participants' comments were partial and indirect, and their common response was they had hopes of retiring from work. Barry (60-year-old male) commented:

I see myself somewhere else from 5 years today definitely. Ten years from today, I will be relaxing somewhere, I'll be 70 and I want be fully retired. Definitely, definitely retired 20 years from today and traveling. I want to be a traveling professor.

Geoffrey (69-year-old male) replied:

Uh, I don't know how long I'm going to be at the Housing Commission. A new administrator a lot of times brings about different type of chemistry. So, I don't see myself 5 years down the road being at the Housing Commission...so, I don't see myself there for 5 years, but as long as I can do the work in the community and will be helping people in the community, uh, through my church, I'm going to do that. I don't see anywhere in the Bible that any of those prophets or men of God retired. I'm chairman of the board of that organization...but see myself continually working...may not be chairman of the board I may be a committee person because I wear different hats I many different situations (10 years). So as long as God says ok Geoffrey, I'm going to say ok to Him. I may not be able to do some things physically...I can't do it like I want to but I can coordinate it, I can be present, I can supervise, I can give support (20 years).

Keith (65-year-old male) noted:

Uh, uh, were if it were 5 years from today if I could be basically or where I am today I'll feel pretty good. I mean if there as any degeneration you know to a significant extent that wouldn't be a good thing at all. You know if I could be doing what I'm pretty much, how I'm doing today, I would be happy with that.

Uh, 10 years from today the only thing I want to discuss is ocean breezes (lots of laughter). Uh, just seeing you and being able to say how you do, shake your hand or whatever. In 20 years that's what I want to do uh, and see the rising again of the morning sun.

Three of the eight participants felt a sense of hopelessness in the situation changing and not able to answer the questions even though I gave multiple prompts. For example, William (65-year-old male) commented:

Oh man, I honestly in 5 years, uh, I probably be wore up and sore up. I don't know it still want be no better in 10 years. No better in 20 years.

**Future Challenges.** There was only one of the eight participants' who responded with a concerned about health status. John (66-year-old male) noted: "I'm hoping that everything is good and no problems (referencing health)." Seven of the eight participants' indirect common response was hoping they have some type of good health. One participant Barry (60-year-old male) commented:

Well, I'm really concern about these pains I'm having in my hands because sometimes I have to like pop my fingers in both hands which is really so painful and is the only challenges. And I hope I don't have to end up any problems with writing in the future. I want to be that person 80 or 90 years old and healthy. Futuristic like I am, if I can be honest with you if I didn't have the mind that I have, I might have been really, really sick...

Bruce (63-year-old male) stated: "Oh yes, yes I expect it (health) to be some challenges."

Keith (65-year-old male) reported: “Uh, I need to change probably to some health eating. Uh, you know, I’m going to try to focus on that as I move forward.”

**RQ2.** The second research question was: What is the experience of African American males diagnosed with FM with the healthcare system? I present one theme that emerged from participants responses about their experiences with the healthcare system.

### **Theme Five**

The one theme (e.g., theme five) that emerged for RQ2 was: “There were trust and confidence in healthcare providers, and medical information was obtained by asking questions, and verbal information received from doctors or nurses, and online.” The participants shared their experiences they had with their healthcare providers and how they go about obtaining medical information about their health.

**Trust and Confidence.** Six of the eight participants expressed their healthcare providers as being compassionate, concerned, helpful, and understanding.

John (66-year-old male) stated:

Her Dr. Rao who is from India she’s compassionate she appears to be concerned and helpful. I have a positive...I think I’ve had her since I’ve going to that hospital. She’s been a good person but I’m not always at the hospital. At one point I did physical...occupational therapy which helped some. She makes it easy for me to understand...In what she’s saying.

Another participant Raymond (56-year-old male) mentioned: “I go see her (referencing his doctor); they renew my medication and check my Fibromyalgia pain out. She try to help me a lot.” Geoffrey (69-year-old male) noted:

My new healthcare provider we just started to deal with each other for over a year now...we're no where I want to be, especially after spending eight years...this one is probably uh 16 months or something like that. Just started with him right after the diagnosis. But I'm just getting started with this doctor and hopefully we can grow together.

**Medical Information.** From the responses of seven of the eight participants, the most common reply was they ask questions to get additional information about FM. For example, the participant William (65-year-old male) stated:

Yes they have to listen to me because when they try to talk back on me I tell them, I tell them, serious business that I can't do nothing without their help and I tell them my problems and they give me information (Sounded angry, assertive and bold).

Geoffrey (69-year-old male) mentioned:

They do have handouts, and uh we sit down at the computer and we will go over lab tests and a lot of it is terminology I don't know...we sit down and talk about it. This Thursday I had a field test for my eyes from my Ophthalmologist, running all this stuff by me I asked him. If you want to know something ask questions. So, anything I didn't understand I would write it down and I would come home and look it up. And then when I go to him I would have a list of what I want to talk with him about, so that's how I approach that. So those questions that I have already have they're written down so that I don't forget them and so make sure we go over them so no matter what said. So, I'll say hold on so I say

this is what we have here I want to finish this so uh we do. So, I think how you start off as being very important.

Bruce (63-year-old male) commented:

Uh, I haven't seen him give me any brochures or anything, I guess the internet or online (to obtain information). They'll verbally explain it verbally. But nothing written...and sometimes I call the VA nurse and they have 24 hour nurse there and most time the nurse take some questions and when I see the doctor which is about once in every 2 months, I have my list of questions for him.

**RQ3.** The third research question was: How do African American males diagnosed with FM utilize the Internet? I present one theme that emerged from participants' responses about how they use the internet.

### **Theme Six**

The one theme (e.g., theme six) that emerged for RQ3 was: "There was limited internet search for education purposes and has found useful, straightforward answers, but not involved in any online FM support or forum groups." The participants verbalized using the internet for looking up health information and they find the websites to give information that's easy to understand and also stated non-involvement with online FM support groups or forums.

**Limited Internet Search.** There were five of the eight participants who reported they use the internet to find more information about their health. For example, John (66-year-old male) shared:

There's a few times I've gone on the internet to look up that name to find out what's it's taken for and sometimes I find out the medication is prescribed for several things. Well as I said I'm not really active in doing this, why because I feel like the medications they have prescribed for me is working.

Bruce (63-year-old male) noted:

Uh I've been using it like every other day or ever 2 to 3 days and uh I use the internet. Uh just go to it and type in symptoms and diagnosis and that's pretty much it and its pretty good information...I just go type in my questions like Google.

Keith (65-year-old male) stated:

Oh just research just getting information uh as to what going on what I can do what uh might, you know options that might be available and so forth on.

**Straightforward Answers.** Five of the eight participants stated they found the FM websites were easy to access and helpful in finding information. Barry (60-year-old male) commented: "The internet provided information about Fibromyalgia and what's new. Well, uh, to be honest with you the only time is when I do my research for school or work." Geoffrey (69-year-old male) reported:

Oh sure they even have illustrations of the pressure points and I say wow (stated with emphasis) they really know what they're talking about. Well, I make a little note for those Wi-Fi I explore and then I make a little note I got a little pad. I don't remember all this stuff so I have a little pad I look at. I'll be talking print something, and discuss, that so I say hold on for a second let's talk about it. It's a

person I talk to it's a one way street I look at the information a lot of times it will send you to another site and I want to see what this got to say what research has been done on how to deal with this or how to deal with that. So, its information out there so, sometimes I make a note so when I go to the doctor, I already go with what I want to talk with him about because I see something on the internet. Keith (65-year-old male) mentioned: "Yes, for me it's pretty easy I don't like the clutter that's on the websites. I mean I don't know why I guess everybody got to make money, but it's just clutter with junk other than that its' ok." Seven of the eight participants answered they have not attended any online FM support groups or forums.

### **Discrepant Case Analysis**

There were seven of eight discrepant cases to Interview Question 5 sub-questions (e.g., sub-questions 2 through 5). These seven of eight discrepant cases were previously addressed under RQ1 theme four and were incorporated into the analysis.

### **Summary**

The purpose of this study was to examine the lived experiences of African American males with FM. In chapter 4, I presented a review of the data collected and how the data was managed and analyzed. The eight participants verbally attested that they understood the Informed Consent before the start of the interview. The responses from the interviews examined what it was like for African American males to live with FM. A descriptive phenomenological method was used, and the appropriate steps were taken to ensure the interpretation of the data attended to the lived experiences shared by the participants (Giorgi, 2009).



In response to the RQ1, most participants commented they had multiple symptoms at the time of being diagnosed with FM. The length of time for obtaining an FM diagnosis varied between each participant as well as the types of diagnostic tests received from healthcare professionals. The participants revealed they had limited support from family and friends. Participants noted they experienced the effects of FM at their place of work. Responses to RQ2 showed the participants had an underlying level of trust and confidence in their healthcare providers treating their illness. They were also able to obtain FM information readily, by asking their healthcare provider questions. Responses from participants to RQ3 demonstrated that the participants' usage of the internet to search for FM information was limited, although they reported the internet was straightforward in finding information. The majority of the participants did not and had never participated in an online FM support group or forum. Chapter 5 will present the interpretation of the research findings, limitations, recommendations, social change implications, and conclusion.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of the present study was to examine the lived experiences of African American males with FM and to determine how they are affected by FM. I used the descriptive phenomenological method to investigate the shared experiences of the participants (Giorgi, 2009). I used this method to gather external and internal experiences that detailed the memories and providing understanding associated with these experiences and images that were connected to past events of the African American male with FM. Insufficient information is available on how FM affects African American males. In most of the previous research literature on FM, participants were females with occasional studies with Caucasian males, Hispanic males, and African American females (Schaefer, 2005). Thus, I conducted this study understand the lived experiences of African American males who encounter the effects of FM in their daily lives.

I formulated three research questions to address specific goals for this study:

RQ1: What are the lived experiences of African American males diagnosed with FM?

RQ2: What is the experience of African American males diagnosed with FM with the healthcare system?

RQ3: How do African American males diagnosed with FM utilize the internet?

I asked these questions of African American males with FM via 10 interview questions, and several themes emerged from the participants' responses.

The key findings for RQ1 were that participants verbalized receiving tests such as x-rays and labs to obtain an FM diagnosis. The primary symptoms expressed by most of the participants was debilitating pain and problems with anxiety and depression. They reported having (a) to learn to cope with pain, (b) difficulty walking even though may denied the need for assistive devices, (c) cognitive challenges such as forgetfulness, and (d) FM symptoms affect work. Nonetheless, the participants reported maintaining hope and confidence. The main findings for RQ2 were that the participants had experienced their healthcare providers as being caring, compassionate, and helpful in providing them with information about FM. The key findings for RQ3 were that the participants used the computer to search the internet for FM information, were able to retrieve relevant information pertaining to their illness, but did not participate in online FM support groups or forums.

### **Interpretation of the Findings**

FM was first recognized in the early 1800s as a type of muscular rheumatism with various symptoms that included stiffness, aches, pains, fatigue, and sleeping problems. Doctors at the time thought inflammation was the origin of pain (Wallace, 1999). Over time, clinical understanding of this illness has evolved, and in 1976 the disorder was renamed FM because researchers determined that inflammation was not the reason for the pain (Wallace, 1999). FM is a medical condition that affects the musculoskeletal and nervous systems. It is more prevalent in females, although males are known to have this illness (Yunas, 2011). FM studies have shown how Caucasian females are affected by FM, and there is some research on how Caucasian males, Hispanic males, and African

American females are affected by FM. However, there is no evidence of how African American males are affected by FM. Some reasons why African American males may not be included in FM clinical research are they are less likely to have medical coverage, which is a prerequisite to access medical practices and enroll in some clinical trials (Swanson & Ward, 1995). African Americans are high users of the emergency rooms due to lack of health insurance (Shavers et al., 1997). The findings in this study did not confirm that participants were unable to access medical care, and neither did they show that participants were high users of the emergency rooms as shown in the peer-reviewed literature. My findings showed that the participants had health coverage, had a primary care doctor and access to other medical specialists, and did not mention experiences associated with the use of emergency rooms to treat their FM.

Individuals living with FM have been reported to make every attempt to adjust to and confront their constant chronic pain and live their lives as normally as possible (Bond & Simpson, 2006). The results of this study showed that the participants had coped in the past in attempt to live as normal a life as possible. The study also showed that this pushing through, a way of coping, was used in the workplace by many of the participants in the study. Bond and Simpson (2006) found that some people are not able to adjust and confront their chronic pain, and thus depend on family, friends, social service agencies, and healthcare services to assist with the challenges connected with FM. My findings did not reveal participants having a greater dependence on family, friends, social service organizations, and healthcare services to help with the issues associated with FM. Once more, the participants in this present study made every attempt to live a normal life. Jain

et al. (2003) showed that individuals with FM described their pain as a burning sensation, sensations of tingling in hands and feet, and searing sharp and deep aching pain. The participants in my study verbalized their FM pain as feeling like a cutting razor blade, tingling in hands, and stiffness. Boer et al. (2014) found a relationship between catastrophizing, increased pain elevations, a greater usage of OTC drugs, and lack of physical activity. Morris et al. (2011) found that pain catastrophizing is more prevalent in patients with FM than in those with any other inflammatory disorder. Catastrophizing causes an avoidant anxiety response to various daily living and physical activities. Participants in my study did not report any catastrophizing whenever they experienced high levels of pain, and neither did the participants mention a greater usage of prescription and OTC drugs. My findings showed that most of the participants had difficulty performing basic physical activities such as yard work and walking long distances, but continued to do the activity regardless of the pain.

Research by Hammond et al. (2010) showed that African American males procrastinate in getting medical care, preventive care, and screenings such as annual physicals, and that they often wait to obtain medical services until after the onset of illness. I found that participants did not delay in obtaining medical care for their FM and were proactive in seeking out their doctors at the time of the FM onset. Further, I found that participants were involved in FM healthcare treatment planning with their doctors.

African American males are at risk for other chronic disorders such as major depressive disorder when co-morbid illnesses such as hypertension, circulatory, and heart problems are present (Ward & Mengesha, 2013). Although my focus was on FM,

findings showed that several of the participants experienced depression due to the debilitating symptoms of FM but not to the extent that the depression decreased their quality of life. I identified six important themes from the participants' answers regarding their lived experiences with FM.

### **Theme One: Lengthy Multiple Medical Evaluations to Receive a Diagnosis**

McNett et al. (2010) found that females frequently receive a battery of tests and prescribed medications during diagnostic preliminaries, whereas doctors may not consider males for these tests and medications when they first present with FM symptoms. The findings in my study did not confirm those of McNett et al. (2010), but instead showed that all eight participants had received pre-diagnostic testing to obtain an FM diagnosis and were prescribed medication to treat the FM symptoms.

The participants reported that the time span to receive an FM diagnosis ranged from 1 month to 5 years. Five of the eight participants stated they were veterans and received medical services from the Veterans Administration (VA) Hospital and civilian healthcare specialists. Seven of the eight participants had several medical tests performed as part of the medical evaluation to receive an FM diagnosis. Only one of the eight participants received just one medical diagnostic test (e.g., lab work) from their doctor to obtain an FM diagnosis. The two tests that were frequently used by the healthcare professionals during the FM diagnostic phase were diagnostic images such as x-rays, and lab work. The study's findings also showed two of the eight participants had received a physical examination as part of the diagnostic workup for FM, where the other six did not get a physical examination. All eight participants experienced

musculoskeletal pain that was debilitating, although they took prescribed medications and OTC medications to treat the FM symptoms. Emphasizing the biological component of the biopsychosocial model, Martinez-Jauand et al. (2012) found that a significant gene factor was linked to FM, which caused increased musculoskeletal discomfort. This factor may be the reason for the musculoskeletal pain described by the eight participants in my study. Several participants also mentioned classic FM symptoms such as numbness, tingling, headaches, problems sleeping, cognitive challenges, and sensitivity to noise. Although Yunas's (2011) study referenced African American females as having problems with inhibited sleep, two out of eight participants in this study expressed sleeping problems, a common symptom, thereby demonstrating a similarity in the two studies.

**Theme Two: Physical Challenges, Physical Limitations, Emotional Issues, Cognitive Issues, Efforts, and Effects of FM at Work**

All of the participants in the present study had experienced ambulatory issues, such as stumbling and falling in public places or home. Four of the eight participants used a cane to help with walking, and three of the eight participants who needed an assistant device, declined to use a cane because of their pride and placing them at risk for having continued ambulatory challenges. The study found one of the eight participants who wanted to use a cane to help with walking but did not have access to it. For those who did not use a cane to assist with walking, the findings showed they would hold onto the stair rails and look down while walking up and down the stairs, make stops while walking and lean against a wall, and carefully enter and exit moving escalators. Five of the eight participants had a veterans' disability accessible parking tag to help assist with

ambulatory issues, which indicated the need for accommodation with their debilitating FM symptoms. Four of the eight participants reported their physical limitations caused them to change the way they exercise and were constricted to other forms of exercise (e.g., yard work), although the pain was felt with the less strenuous activities.

Four of the eight participants had experienced emotional issues such as embarrassment after falling in front of strangers who fail to render help, had feelings of edginess and being uptight, experienced depression and frustration, and disliked people touching their body due to the pain it caused and therefore developed an avoidance coping mechanism. Ward and Mengesha's (2013) study revealed poor relationships, economic burdens, social problems, and various forms of discrimination for a specific duration, were all factors that contributed to an impaired major depressive disorder and quality of life for African American males. The four of the eight participants, who verbalized depression in theme one and theme two, indicated the pain caused them to feel depressed, and that other life events such as economic burdens, social problems, and poor relationships were not the cause.

The biopsychosocial model (Engel, 1977) was used in the current study and showed how experienced biological factors such as pain could be a possible reason for the depressed feelings reported by the participants. Five of the eight participants had experienced the cognitive problem of forgetfulness and fogginess of the mind which increased their level of frustration toward their FM disorder. Yunas (2011) also showed that African American females experienced cognitive deficits such as fogginess and poor



concentration, which is similar to the findings of this current study for African American males.

The present study's findings revealed six of the eight participants used efforts such as avoidance and perseverance in dealing with the symptoms of FM. Five of the eight participants shared that their job duties required them to be physically and mentally active (e.g., walking, climbing stairs, and facilitating meetings), and that these job duties were affected by the FM pain. Three of the eight participants were not able to work due to health-related issues, but had a past work history performing manual labor such as laundry work, kitchen work, and construction work, which caused body pain. The present study's findings confirmed Allaire et al.'s (2013) study that demonstrated individuals with FM had challenges performing manual labor as well as desk jobs that required repetitive movements. Two of the eight participants reported FM did not affect their job and later verbalized FM symptoms influenced their work and thereby a level of denial was demonstrated by the participants. Four of the eight participants reported their immediate supervisor and employer was not aware of their FM disorder. Allaire et al.'s (2013) study showed employers might not be supportive of the employee with FM due to the disorder not being easily observed which could lead to FM related work problems.

The participants shared experiences where they needed accommodation at work, and they declined to make the employer aware of their illness, thereby confirming Allaire et al.'s (2013) study's findings. The study of Allaire et al. (2013) mentioned when work environments do not provide accommodations for the employee with FM, then the risk for seeking disability will increase. Eight participants had disability benefits, and five out

of eight participants were disabled veterans and seemed to take pride in their work, although they had problems with their FM symptoms; thereby not supporting Allaire et al.'s (2013) study because these study participants desired to work even though they had disability benefits. The present study's findings revealed five of the eight participants were at or above retirement age and three of the eight participants were between the ages of 56 years-of-age and 63-years-of-age. The average age for this study was 64-years-of-age and having the option to retire was found in theme four.

### **Theme Three: Limited Physical and Emotional Support from Family and Friends**

The present study's findings showed that family and friends were minimally supportive and interested and needed to be educated about FM. For three of the eight participants, the results revealed they had few friends and these friends seemed not to understand the pain experienced. The diary notes for this study showed the participants' expressed emotions of anger and sadness about not having full support from friends and family. One of the seven participants reported no family support because in the past he served a lengthy prison sentence and was never contacted by his parents and siblings. Another participant commented that he shared more information about his health while being interviewed than he ever had shared with family members, which showed a reluctance to talk with family members about FM. The study of Soderberg et al. (2003) found that family members of people with FM are faced with issues such as reassignment of household tasks, financial pressures due to health expenses, and children must make adjustments to the new normal life of a person with FM. The present study results showed the participants' family members were limited caretakers, and the children had to

make changes to activities due to FM, but there were not any shared experiences of any financial stress, thereby confirming Soderberg et al.'s (2003) study.

**Theme Four: Hopeful about Work, Plans to Make Work Better in 5 Years, 10 Years, and 20 Years, and Future Challenges**

Five of the eight participants in the current study used prayer and religious beliefs to maintain work optimism and described work as an ordained ministry. The participants used biblical verses to provide self-justification to cope with the FM symptoms while at the job and confirmed Debnam et al.'s (2012) study, which showed a person's higher power is regarded to have an essential part in all areas of the African American life.

Findings of the present study revealed seven of the eight participants provided partial and indirect responses to interview question 5 sub-questions that addressed what needed to make their current work situation better in 5 years, 10 years, and 20 years. Five of the eight participants saw themselves retired in 5 years, 10 years, and 20 years. The study of Rakovski et al. (2012) showed there is an increased likelihood of an individual with FM resigning from their job or being released by the employer, both of which leads to unemployment. The results of the current study were different from Rakovski et al.'s (2012) study because the participants used their faith-based beliefs to maintain contentment with work and shoes not to retire although they were eligible, and thereby the study did not support Rakovski et al.'s (2012) study.

**Theme Five: Trust and Confidence in Healthcare Providers, Medical Information Obtained by Asking Questions, Verbal Information Received from Doctors, Nurses, and Online**

Six of the eight participants reported confidence in their healthcare providers and described them as being compassionate, concerned, and helpful. The present study's findings revealed several participants had to assert themselves to get their doctors to listen to them during the scheduled appointment. Although seven of the eight participants expressed asking questions of their healthcare providers to obtain information, the doctors did not readily give the FM information without being requested multiple times. Hammond et al.'s (2010) study showed African American males delay in getting medical treatment and wellness screenings such as cholesterol and blood pressure checks, and annual physicals, as well as put off medical care after the onset of an illness with the result that the disorder is more of a challenge to the treating doctor. Results from the current study found all of the participants had taken the initiative to see their healthcare provider at the time they became symptomatic, they received preliminary diagnostic evaluations with no hesitation, and they advocated for their healthcare needs, contrary to the study of Hammond et al. (2010).

**Theme Six: Limited Internet Search for Education Purposes, and Useful, Straightforward Answers, and Not Involved in Online FM support or Forum Groups**

Findings of the present study demonstrated three out of eight participants did not use the internet to search for additional FM information. Five of the eight participants mentioned they used the internet to search for FM information and found the internet easy to use, the FM websites' terminology was not difficult to comprehend, and the internet provided answers in a simple context, whereas one of the eight participants

mentioned the internet sites contained a large volume of clutter. The web usage for the participants was not extensive and was limited to intermittent information searches. Mitchell et al.'s (2014) study showed the lack of engagement in searching the internet for information that is health-related might add to the African American males' health disparities. Although the internet was simple to access, the results from the present study demonstrated there was limited use of the web, which confirmed the study of Mitchell et al. (2014). Darez et al.'s (2011) study demonstrated the internet has limitations and the educational information on the websites are not clear and the websites may have language that is hard to understand. One of the eight participants actively participated in an FM support group at the VA Hospital, but there was no participation in an online FM support group or group forum. Seven of the eight participants responded that they did not participate in an online FM support group or group forum.

### **Limitations of the Study**

The study intended to recruit a sample of African American males with FM from the FM websites online group forums, but a major challenge of the current study was in recruiting participants from the FM websites, as originally planned and a total of 5 months were spent on recruiting. The process was to make contact with the FM website Coordinators, to obtain a commitment to post my research flyer after approval from Walden University IRB in March 2017, to collect data and efforts were made to recruit participants. I attempted to recruit African American males with FM by requesting to post research ads on the FM websites that had members who were African American males. Two African American FM website Coordinators were emailed, and they posted

the research flyer on their website announcement board. The study received no interest from members of the two African American FM websites, although the two Coordinators, who were African American females, re-posted the research flyer multiple times to their FM website announcement board. Recruitment efforts for the two African American FM websites were ineffective, and thereby a third FM website (e.g., all males) Coordinator was emailed, and the request to post the research flyer was under review. Multiple email follow-ups were sent to the third FM website Coordinator, and the contact efforts were not successful, thereby the research flyer was not posted on the FM website, and this led to an unsuccessful recruitment of African American males.

I emailed a request to post the research flyer in early April 2017 to 36 FM and Chronic Pain Meetup groups across the United States. Six Meetup group facilitators responded, and four out of six moderators stated they would post the research flyer on the notification board, and two out of six facilitators said they did not have any African Americans in their Meetup groups but were willing to share the research flyer with other FM Meetup groups.

In the effort to increase the number of participants recruited, I revised the research flyer to include three pictures of African American males with FM. I submitted a Request for Change in Procedures Form to the Walden University IRB in late March 2017 asking to post a new research flyer on social media LinkedIn. There were views of the research flyer by LinkedIn members, but no response to participate in the study and thereby unable to recruit any African American males with FM from social media. The approved research flyer was sent to two African American FM website Coordinators who

posted the flyer on their FM website announcement board, and no participants were recruited from this effort.

In mid-April 2017, I submitted the second Request for Change in Procedures Form to Walden University IRB, and I requested to add a \$10.00 Starbucks Gift Card compensation and my picture to the research flyer to indicate the researcher was African American, in efforts to increase the numbers of African Americans recruited. I sent the last Request for Change in Procedures Form to Walden University IRB in late June 2017 due to problems encountered with the Walden University Office 365 Outlook, and asked to add my private email address to the research flyer as included in Appendix F, and consent form, as found in Appendix E.

In mid-April 2017 and mid-June 2017, I used the snowball method to increase the number of participants. The snowball method included sending research flyers to my social network to post in African American communities, and I also asked an African American physical therapist office to post the ad on the bulletin board. I requested African American churches to post on the announcement board, and I posted ads in the African American barbershops, and in the African American community grocery stores (e.g., Kroger's).

I attended the Fibromyalgia Association of Houston (FMA-Houston) in early May 2017, and the group consisted of Caucasian females and males, Hispanic females and African American females and they were not aware of any African American male FM groups in Houston, Texas and across the United States. In late May 2017 contact was made to an African American FM group in Louisiana and the facilitator expressed she

knew African American males with FM but lost touch, and there were no African American males in their group, but the moderator was willing to post the research flyer.

The snowball method and the changes made to the research flyer were useful. I interviewed the first FM participant in late May 2017, and the last participant was interviewed in mid-August 2017. The participants found out about the study from churches, barbershops, and word of mouth from African American males who were veterans. Two of the eight participants who interviewed for the study verbalized they preferred not to receive \$10.00 Starbucks Gift Card compensation because they never had this opportunity before to share their lived experiences with FM.

A limitation of the current study was that three of the eight participants highest level of education was a GED, and they gave a simple yes or no to the 10 interview questions and had difficulty in offering detailed information, whereas multiple prompts had to be provided in the attempt to obtain a response. The reasons the three participants with a GED was not as responsive was due to a history of being sentenced to a confined criminal justice institution for 15 to 20 years and part of the time was restricted to a single cell. Because there were five of the eight participants who held post-graduate degrees, this afforded them resources and knowledge that the average person does not have in being able to provide detailed answers to the 10 interview questions with fewer prompts than the participants with a GED.

Another limitation was, three of eight participants had a GED and were not presently employed although they had a history of performing labor work (e.g., construction and kitchen work), and the blue collar jobs would be hard to accomplish



with the current FM challenges. The type of employment available to the three of the eight participants with a GED was limited, and several of the GED participants had acquired Supplemental Security Income (SSI), and another GED participant had Social Security Disability Insurance (SSDI), thereby they had access to medical care and medications.

Another limitation of the study may have been the construct of the interview questions. The participants with a GED had difficulty with the open-ended questions framework, and my response was to prompt by asking many questions which may have lacked the benefits of the open-ended format, and resulted in a pattern of questioning and answering with minimum free-flowing lived experiences. There was a major limitation from Interview Question 5 and its sub-questions that addressed feelings toward their current work situation and what would need to happen to make them feel good about their work situation. The participants with the GED was not able to answer the Interview Question 5 due to not presently working, but made attempts to answer Interview Question 5 from the work they performed before incarceration and the assigned work while incarcerated. The GED participants tried to answer interview question 5 sub-questions but would often verbalize hopelessness and not know how to answer Interview Question 5 sub-questions of what needs to happen for them to feel good about their situation related to work 5 years from today, 10 years from today, and 20 years from today. The participants, with a post-graduate degree, were able to answer Interview Question 5. But Interview Question 5 sub-questions they answered partially with details surrounding of

how they viewed (e.g., retired, traveling professor, and having others run their private business) in 5 years from today, 10 years from today, and 20 years from today.

Another limitation was the GED participants did not have access to a computer and therefore were not internet users and did not visit FM forum and support group websites. The post-graduate participants were limited internet users and did not visit FM forum and support group websites, but did attend a chronic pain support group at the VA Hospital.

Although the rigor of the study successfully provided a convenience sample, the generalizability is restricted to older African American males with chronic pain. Additionally, any generalizations to other males with chronic pain illnesses may be limited to other populations. Another limitation is although the study age range was from 18 years of age and older, the study population represented the older adult population and the study may not be transferable to young adult African American males with FM. Another limitation is the study is not generalized to females and minors. The background data, the framework of the study, and the detailed description of this study is sufficient for any future comparisons to be made with populations that are comparable (Shenton, 2004).

### **Recommendations**

The study increased the understanding of the lived experiences of African American males with FM. Brewer and Cooper (2014) found race consciousness has been expressed as one who has an apprehension of being vulnerable to the possibility of being discriminated against. African American males were found difficult to recruit for this

research, and thereby the study experienced challenges in recruiting African American males with FM and race consciousness was considered. To increase the recruitment efficacy for this population, some steps should be considered for future researchers.

First, the research ad was altered from a less formal to a diversified cultural ad that invited the targeted population to be part of advising on the research topic. Second, the participants should be referred to by their last names (e.g., Mr./Dr. Smith) unless permission is received to address them by their first names. Sensitivity and understanding cultural diversity to the values of African American participants is important when speaking with the participants by telephone or face to face. Also, it is important to respond to older African American males' questions by stating yes-sir or no-sir, which indicates a level of respect and sensitivity to the older African American male.

Lastly, faith-based institutions are part of the African American culture, and these institutions are essential for the recruitment as justified by the participants found out about the present study through their churches. Lumpkens et al.'s (2011) study found that African Americans often observe the religious institution as being honorable and credible and the clergy is viewed as a guiding force in all areas of their life. The recommendation is that future research expands the study to African American religious institutions, VA Hospitals chronic pain groups (e.g., this study had five veteran participants), because the VA Hospitals have a diversified population. Other recommendations for recruiting participants are to partner with African American health clinics and county multipurpose centers located in the African American communities before conducting a study with African American males. By considering these

recommendations into consideration, the recruitment process could be less problematic for future research, and the population could fairly be represented from the recommendations presented.

Another recommendation is to consider the education level of the African American male, whose highest level of education is a GED, because of the difficulty they have in comprehending an open-ended interview question. I would recommend having a person with a GED level of education to participate in a survey type of study versus an interview with the open-ended questions, thereby preventing the multiple prompts the interviewer would have to give in attempt to obtain an answer to an open-ended interview question.

### **Implications**

Many opportunities exist to make positive change for African American males who are diagnosed with FM. The findings from the current study can positively add to the current body of literature used to understand older African American males' lived experiences of FM, although a larger representation of the population would need to include a broader age range to determine the lived experiences for a younger population versus an older population are different.

It was apparent that the African American males with a post-graduate degree were able to provide large accurate accounts of their experiences and how FM affected their life. But the African American males who had a GED level of education provided minimum factual accounts because of the difficulty they experienced in answering the open-ended questions. Thereby the results of this study could have been different if I

would have considered doing a survey type of study. Another positive social change that can provide educational information for healthcare providers is that African American males with FM are found to use traditional medicine treatments to treat their FM, but they depend mostly on their faith-based beliefs to help them cope with the FM symptoms at home, in the community, and at work.

Finally, the findings from this study determined the older African American males with a post-graduate degree made limited use of the internet and had never attended an online FM group forum, but had attended a chronic pain group at the VA Hospital. The GED participants had no access to a computer and had no interest in learning how to use the computer to access information and no interest in attending online FM group forums. Because I wanted to look at African American males who used the internet for FM educational purposes, the study did not have enough participants to provide any real conclusions with the exception of those who had a post-graduate degree accessed the computer when looking up information about FM. A larger population with a broader range of age and education and is needed to see if African American males utilized the internet and online FM group forums.

The major issue was recruiting participants, and the current study does not provide a good representation of the population of young adult African American males with FM, and thereby it may not accurately reflect the lived experiences of young adult African American males with FM. The findings from this study could be regarded as a foundational consideration for healthcare professionals and caregivers.

## Conclusion

The present descriptive phenomenological study focused on the phenomenon of FM, and investigated the participants' types of lived experiences, identified what information could be learned, as well as how these experiences changed the quality of life (Giorgi, 2009). The experiences of the African American males with FM was expressed through recorded interviews and provided accurate descriptions that established significant themes that led to a better understanding of the phenomenon of African American males with FM.

The current study extends the present knowledge about the lived experiences of FM to the lived experiences of African American males with FM and how they daily life are affected. As a result of this study, the reality statement which described the phenomenon of the African American with FM is: "Living with FM is very debilitating and painful to cope with on a daily basis. African American males deal with the FM symptoms by depending on their faith-based beliefs to provide them with hope and strength to face each day."

In conclusion, the older African American males with FM were grateful to articulate how FM has affected their lives, as well as being able to use their shared information to help educate healthcare professionals, caretakers, and local and national FM Associations. The lived experiences of older African American males with FM is learning how to accept FM and longing for the healthy life they once had before FM.

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## Appendix A: History of Fibromyalgia

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1. Thought to be a psychiatric disorder, the first description of FM was noted in the account of Job (after 2350 BC and before 1750 BC) as referenced in the Bible. The account of anguish and in constant pain in the skeletal system, Dr. Daniel J. Wallace, a rheumatologist, gave these symptoms to meet the criteria of Fibromyalgia (Wallace, 1999).
  2. In the late 1700s early 1800s, FM was described as part of the rheumatic classification system. Written accounts are given to an ailment referenced as “muscular rheumatism (Wallace, 1999).” The symptom description, was stiffness, aches, pains, tiredness, and bouts with insomnia.
  3. In the beginning of the 1820s, a physician in Scotland first identified the tender sites of FM.
  4. Early 1900s the medical terminology of ‘fibrositis’ was initially spoken by doctors to help classify the inflammation or swelling that was once believed to be the primary reason for the level of pain experienced by patients. Thereby the prefix ‘it is’ was given to denote some sort of medical disorder.
  5. As medical science progressed, the name fibrositis was no longer the correct medical context, because inflammation of the body was not believed to be the reason for the root of the pain. Thereby, for describing this musculoskeletal disorder, the name Fibromyalgia was given in its place, in 1976.
  6. The term Fibromyalgia is taken from Latin and Greek words.
  7. *Fibro* (Latin) means fibrous tissue and has to do with painful tendons and ligaments –
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*Myos* (Greek) means muscle – *Algos* (Greek) means pain.

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## Appendix B: Empirical Research Studies That Give Credence to Fibromyalgia as a Real

## Medical Condition

<b>Year</b>	<b>Event</b>
1981	The first medical study done by scientists to solidify that symptoms and tender points could be found in the body.
1990	The American College of Rheumatology is given credit for creating the first set of guidelines to help diagnose FM.
2005	The first guidelines for treating FM pain were published by the American Pain Society.
2007	The first prescription medication was FDA approved to manage FM.

## Appendix C: Interview Instrument

RESEARCH QUESTION	INTERVIEW QUESTIONS
<b>RQ 1: What are the lived experiences of AA males diagnosed with FM.</b>	IQ1: Tell me how you were diagnosed with FM?
	IQ2: Tell me what have you experience since being diagnosed with FM?
	IQ3: How did you and your family react to diagnosis of FM? How did your friends react to your diagnosis of FM?
	IQ4: Tell me about your job and FM, have you seen any effects? Tell me about this.
	IQ5: How are you feeling about your current situation related to work? Follow Up Question: If we were meeting 5, 10, 20 years from today, what needs to happen for you to feel good about your situation related to work? Follow Up Question: What challenges do you see in making this happen?
<b>RQ 2: What is the experience of AA males diagnosed with FM with the healthcare system?</b>	IQ6: What is your experience with the healthcare providers since being diagnosed with FM?
	IQ7: How do you obtain medical information from your healthcare providers on FM?
<b>RQ3: How do AA males diagnosed with FM utilize the internet?</b>	IQ8: How did you go about using the internet after being diagnosed with FM?
	IQ9: In what way do you feel the FM websites are helpful?
	IQ10: How often do you use the FM support groups and / or forums? Follow Up Questions: In what ways are the FM support groups are helpful? Follow Up Question: In what ways are the FM forums helpful?

## Do You Have Constant Overall Body Aching?



*Do You Have or Does Somebody You Know Have Overall Body Aching,  
Known as Fibromyalgia?*

- Very little is known about how male African Americans experience Fibromyalgia.
- **We are in need of advice** from African American males with overall body aching Fibromyalgia (ages 18 years & older).
- If you agree to be in this study, you will be asked to provide advice and feedback to a set of 10 interview questions that will last 30 minutes to 1 hour.

*If you are accepted in the study, you will receive a \$10.00 Starbucks Gift Card as a thank you.*

You can contact the researcher Ethel Perry, via phone number XXX-XXX-XXXX and/or email address [ethel.perry@waldenu.edu](mailto:ethel.perry@waldenu.edu)